Some Thoughts About Dying Well

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End-of-Life Factors Rated as Very Important by more than 90% of Patients & Physicians

Attributes	
Be kept clean	Be free of pain
Name a decision maker	Say goodbye to important people
Have a nurse with whom one feels comfortable	Be free of shortness of breath
Know what to expect about ones physical condition	Be free of anxiety
Have someone who will listen	Have a physician with whom on can discuss fears
Maintain one's dignity	Have financials in order
Trust one's physician	

Steinhauser et al. JAMA. 2000;284:2476-2482

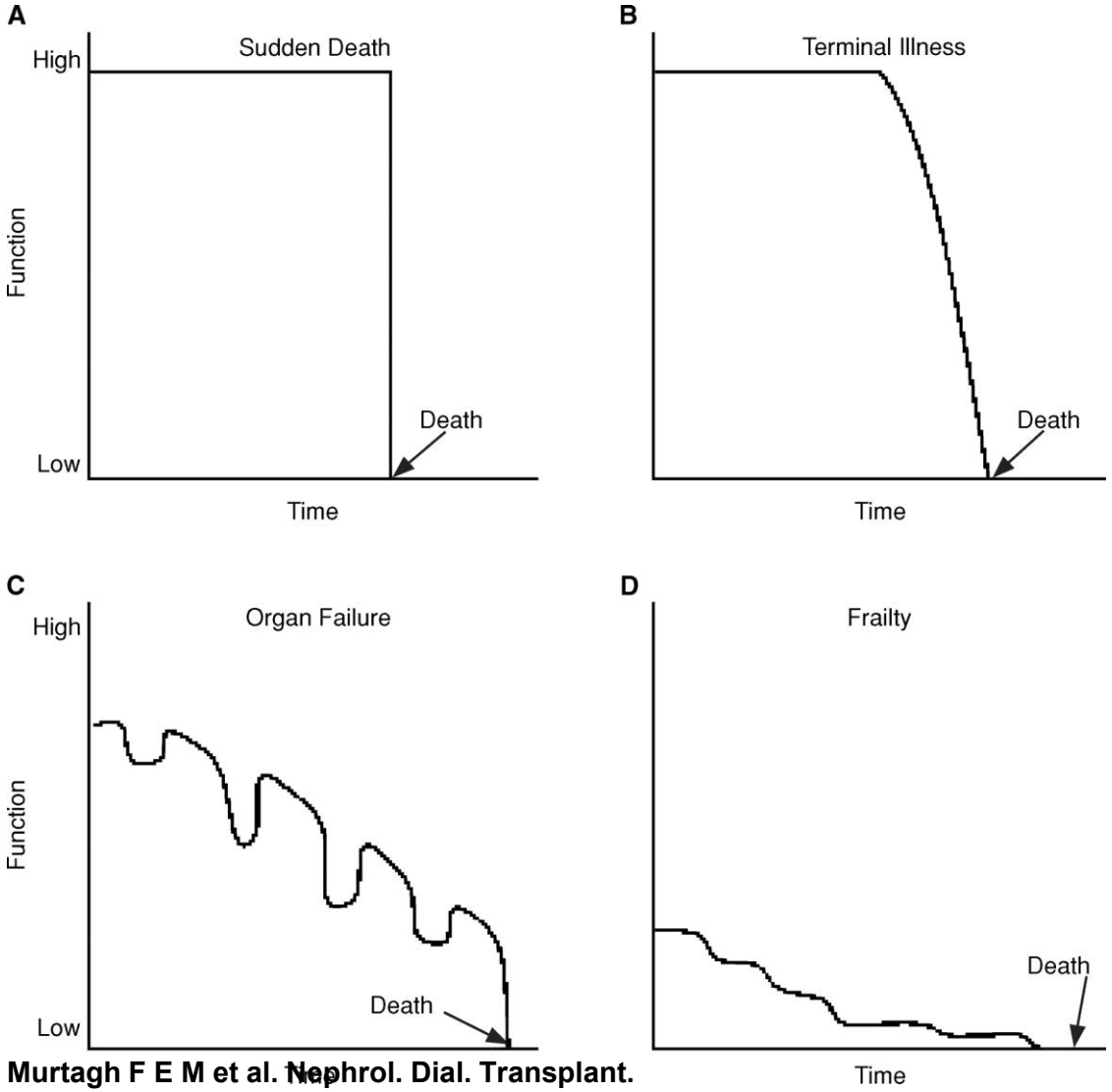
End-of-Life Factors Rated as Very Important by Most Patients but not Physicians

Attributes	Patients	Physicians
Be mentally aware	92%	65%
Be at peace with god	89%	65%
Not be a burden to family	89%	58%
Be able to help others	88%	44%
Pray	85%	55%
Have funeral arrangements planned	82%	58%
Not be a burden to society	81%	44%
Feel one's life is complete	80%	68%

*P<.001 for all comparisons

Steinhauser et al. JAMA. 2000;284:2476-2482

The typical disease trajectories identified in patients with different diseases.



Murtagh F E M et al. Nephrol. Dial. Transplant. 2008;23:3746-3748

THE RIGHT TO DIE

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In the absence of written documents, some states require clear evidence that the patient specifically mentioned certain things.

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In the absence of written documents, some states hold Surrogate decision makers to higher standards about hydration and nutrition.

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Death is caused by the illness not by the treatment decision.

Changing Goals

"The goal of a peaceful death should be as much a part of the purpose of medicine as the promotion of good health. That means medicine must abandon the modern cultic myth that *in the cure of disease lies the cure of death*…..Disease and death will have their day."

Daniel Callahan

WHAT IS PALLIATIVE CARE
WHO (World Health Organization)

Palliative care is an approach that improves the ***quality of life*** of patients and their families facing the problem associated with ***life-threatening illness***, through the ***prevention and relief of suffering*** by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Further definition of Palliative Care

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provides relief from pain and other distressing symptoms;

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integrates the psychological and spiritual aspects of patient care;

Palliative Care is not just Hospice

It is applicable ***early*** in the course of illness, *in conjunction with other therapies that are intended to* ***prolong life***, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Dying with Dignity

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- Palliative care is whole-person care that relieves symptoms of a disease or disorder whether or not it can be cured.
- You can receive palliative care at any stage of a serious illness, whether that illness is potentially curable, chronic or life-threatening.

Dying with Dignity

Hospice is a specific type of palliative care for people who likely have six months or less to live.

Hospice is a form of Palliative Care

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Hospice care is provided by an interdisciplinary team.

What’s covered by Hospice

Time and services of the care team, including visits to the patient’s location by the hospice physician, nurse, medical social worker, home-health aide and chaplain/spiritual adviser

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Medication for symptom control or pain relief

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Medication for symptom control or pain relief

Medical equipment like wheelchairs or walkers and medical supplies like bandages and catheters

What’s covered by Hospice

Physical and occupational therapy

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Speech-language pathology services

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Dietary counseling

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Dietary counseling

Any other Medicare-covered services needed to manage pain and other symptoms related to the terminal illness, as recommended by the hospice team

Treatment NOT covered by Hospice Benefit

Treatment intended to cure a terminal illness or unrelated to that illness

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Prescription drugs to cure a illness or unrelated to that illness

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Room and board in a nursing home or hospice residential facility

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Prescription drugs to cure a illness or unrelated to that illness

Room and board in a nursing home or hospice residential facility

Care in an emergency room, inpatient facility care or ambulance transportation, unless it is either arranged by the hospice team or is unrelated to the terminal illness

Dying with Dignity

Hospice is a specific type of palliative care for people who likely have six months or less to live.

In other words, hospice care is always palliative, but not all palliative care is hospice care.

Dying with Dignity

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Advanced Health Care Directive

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Power of Attorney for Health Care (to appoint an agent)

Instructions for Health Care (to indicate your wishes).

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Often many family members *are* involved in decision-making. And most of the time, that works well. But occasionally, people will disagree about the best course of action, so it is usually best to name just one person as the agent (with a back up, if you want). And you can also indicate if there is someone who you do NOT want to make your decisions for you.

NO Advanced Directive

What if something happens to me and no form has been completed?

NO Advanced Directive

What if something happens to me and no form has been completed?

If you are not able to speak for yourself, the doctor and health care team will turn to one or more family members or friends. The most appropriate decision-maker is the one with a close, caring relationship with you, is aware of your values and beliefs and is willing and able to make the needed decisions.

What I want?

What kinds of things can I write in my Instructions for Health Care?

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What kinds of things can I write in my Instructions for Health Care?

You can, if you wish, write your preferences about accepting or refusing life-sustaining treatment (like CPR, feeding tubes, breathing machines), receiving pain medication, making organ donations, indicating your main doctor for providing your care, or other things that express your wishes and values.

What form to use?

Can I make up my own form or use one from another state?

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Yes. That's why this law is so flexible. Any type of form is legal as long as it has at least 3 things: 1) your signature and date, 2) the signature of two qualified witnesses, and 3) if you reside in a skilled nursing facility, the signature of the patient advocate or ombudsman. These signatures, however, must include special wording.

In Missouri, The Show Me State, the signatures have to be NOTARIZED.

Attorney needed?

Sounds difficult. Do I need an attorney to help with this?

Attorney needed?

Sounds difficult. Do I need an attorney to help with this?

No. Completing an advance health care directive isn't difficult and an attorney is not necessary. But actually **the most important part of this is talking to your loved ones.** Without that conversation, the best form in the world may not be helpful!

Change of heart

What if I change my mind?

Change of heart

What if I change my mind?

You can revoke your form (or your oral instructions) at any time. Also, it's a good idea to try and retrieve old forms and replace them with new ones.

Advance Care Documents

Missouri and Kansas Advance Directives

Caring info.org

Thinking Ahead

Coalition for Compassionate Care of California – COALITIONCCC.ORG

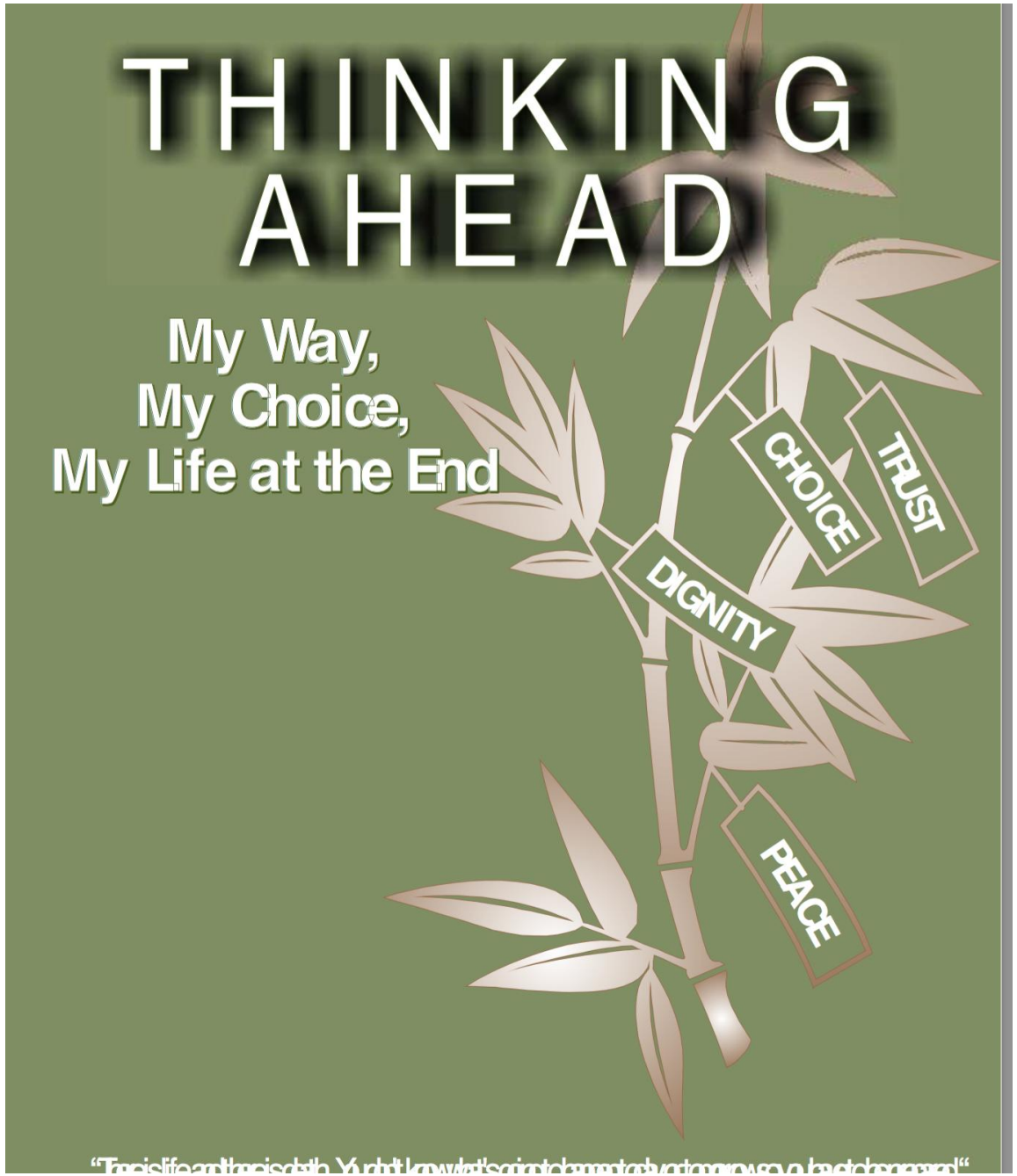
SUPPORTEDDECISIONMAKING.ORG

Psychiatric Advance Directive

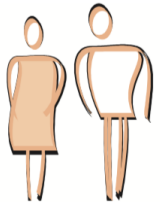
www.nrc-pad.org

TPOPP

Missouri and Kansas Medical Societies


THINKING AHEAD
My Way,
My Choice,
My Life at the End
TRUST
CHOICE
DIGNITY
PEACE

Choosing the Right Person to Help



Everyone needs help when thinking ahead and carrying out plans at the end of his or her life. Choosing a **Trusted Helper** to help you complete this workbook is the first step. This person should be comfortable talking with you about end-of-life choices. Think about who can help you.

THINK – Who Can Help Me

Someone who:

- Knows me well and cares about what is important to me.
- Helps without telling me what they think I should do.
- Listens to me and is respectful.
- Will advocate for me.
- Will help me complete this workbook.

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NRC•PAD
NATIONAL RESOURCE CENTER ON PSYCHIATRIC ADVANCE DIRECTIVES

"This time, with a PAD, I did not receive any treatments that I did not want. They were very respectful. I really felt like the hospital took better care of me because I had my PAD. In fact, I think it's the best care that I've ever received."
Read More PAD Stories...

Getting Started | State by State Info | FAQs | Videos | Links | Current Research | In the News | Legal Issues

TPOPP Form

FORM SHALL ACCOMPANY PERSON WHEN TRANSFERRED OR DISCHARGED

Kansas – Missouri Transportable Physician Orders for Patient Preferences (TPOPP/POLST)

This Medical Order set is based on the patient's current medical condition and preferences. Any section not completed indicates default treatment for that section. The original form need not be present at the time of emergency. A copied, faxed or electronic version of this form is valid.

Last Name:	First Name, MI:	
Date of Birth:	Last 4 SSN or Patient ID#:	

A. CHECK ONE — **CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing. If patient is not in cardiopulmonary arrest, follow orders in B and C.**

- ☐ **Attempt Resuscitation/CPR** *(Selecting CPR in Section A requires selecting Full Treatment in Section B)*
- ☐ **Do Not Attempt Resuscitation** *(DNAR/no CPR/Allow Natural Death)*

B. CHECK ONE — **INITIAL TREATMENT ORDERS: Follow these orders if patient has a pulse and/or is breathing.**

Reassess and discuss treatments with patient and/or representative regularly to ensure patients care goals are met.

- ☐ **Full Treatments (required if CPR chosen in Section A).** GOAL: Attempt to sustain life by all medically effective means. Provide appropriate medical treatments as indicated in an attempt to prolong life, including intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion, including intensive care.
- ☐ **Selective Treatments.** GOAL: Attempt to restore functions while avoiding intensive care and resuscitation efforts (i.e., ventilator, defibrillation, and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.
- ☐ **Comfort-focused Treatments.** GOAL: Attempt to maximize comfort through symptom management only; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or selective treatments unless consistent with comfort goal. Transfer to hospital if comfort cannot be achieved in current setting.

C. CHECK ONE — **MEDICALLY ADMINISTERED NUTRITION: Offer food by mouth if desired by patient, is safe and tolerated.**

- ☐ Provide feeding through new or existing surgically-placed tubes
- ☐ Trial period for medically assisted nutrition but no surgically-placed tubes
- ☐ No medically assisted means of nutrition desired
- ☐ Not discussed or no decision made

D. **ADDITIONAL ORDERS OR INSTRUCTIONS FOR SECTIONS B AND C:** Includes e.g., time trials, blood products, and other orders. [EMS Protocols may limit emergency responder ability to act on orders in this section.]

E. CHECK ALL THAT APPLY — **INFORMATION AND SIGNATURES (E-Signed documents are valid)**

Discussed with:

☐ Patient ☐ Agent/DPOA Health Care ☐ Parent of minor ☐ Legal guardian
☐ Patient Representative ☐ Other *(specify)*: _____

Signature of patient or recognized decision maker (all fields required): By signing this form, the patient/recognized decision maker voluntarily acknowledges that this treatment order is consistent with the known desires and/or best interest of the patient.

Print name:	Signature:	The most recently completed valid TPOPP/POLST form supersedes all previously completed TPOPP/POLST forms.
Address:	Relationship:	Phone:

Signature of authorized healthcare provider (all fields required): My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences. (verbal orders are acceptable with follow up signature)

Print name of authorized provider and/or Physician:	Phone:
Signature of authorized provider:	Date:

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AND PROXY DECISION MAKERS AS NECESSARY FOR TREATMENT

Kansas-Missouri TPOPP practicalbioethics.org

FORM SHALL ACCOMPANY PERSON WHEN TRANSFERRED OR DISCHARGED

Patient Last Name:	First Name, MI:	DOB:	Last 4 SSN/Patient ID#:

ADVANCE CARE DIRECTIVES & EMERGENCY CONTACTS

Review of Advance Directives (Check all that apply)

- ☐ Healthcare Directive (Living Will)
- ☐ Other Instructions or Documents
- ☐ Advance Directives Unavailable
- ☐ No Advance Directives Exist
- ☐ Appointment of Durable Power of Attorney for Health Care (Name):_____ (Phone):_____

Patient's Emergency Contact (if other than person signing form) and Provider(s)

Full Name:_____ Phone (voice __ text __): _____

Primary Care Provider Name: _____ Phone: _____

Hospice Care Agency (If Applicable) Name: _____ Phone: _____

Health Care Providers and Others Assisting with Form Preparation Process (Check all that apply)

- ☐ Social Worker
- ☐ Health Care Agent
- ☐ Patient Advocate
- ☐ Nurse
- ☐ Parent of Minor
- ☐ Legal Guardian
- ☐ Clergy
- ☐ Family Member
- ☐ Other: _____
- ☐ Palliative Care Provider
- ☐ "Person of Care and Concern"

Instructions for Completing TPOPP/POLST

- Completing a TPOPP/POLST form is always voluntary. TPOPP/POLST is a useful tool for the understanding of and implementation of physicians' orders that are reflective of the current medical condition and preferences of a patient. The orders are to be respected by all receiving providers in compliance with institutional policy. On admission to the hospital setting, a physician who will issue appropriate orders for that inpatient setting will assess the patient.
- TPOPP/POLST is a physician order set and as such does not replace Advance Directives but should serve to clarify them.
- TPOPP/POLST must be completed by a health care provider based on patient preferences and medical indications. Upon completion it must be signed by a physician, APRN, or PA in compliance with state law, regulation, and scope of practice; and by patient *(or representative)* to be valid.
- Photocopies and Faxes of signed TPOPP/POLST forms are valid. Use of original form is strongly encouraged. A copy shall be retained in patient's medical record and accompany the patient to all settings.

Using TPOPP/POLST

(Any incomplete section of TPOPP/POLST implies full treatment for that section).

- **SECTION A:**
  - If found pulseless and not breathing, no defibrillator *(including automated external defibrillators)* or chest compressions should be used on a person if "Do Not Attempt Resuscitation" is selected.
- **SECTION B:**
  - When comfort cannot be achieved in the current setting, the person, including someone with "Comfort-focused Treatments" should be transferred to a setting able to provide comfort *(e.g., treatment of a hip fracture)*.
  - Non-invasive positive airway pressure includes continuous positive airway pressure *(CPAP)*, bi-level positive airway pressure *(BiPAP)*, and bag valve mask *(BVM)* assisted respirations.

Reviewing TPOPP/POLST

- TPOPP/POLST form should be reviewed when:
  - The person is transferred from one care setting or care level to another, or
  - There is a substantial change in the person's health status, or
  - The person's treatment preferences change, or
  - The care provider changes.

Modifying and Voiding TPOPP/POLST

- A patient with capacity can, at any time, request alternative treatment or revoke a TPOPP/POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating.
- A legally recognized decision-maker may request to modify the orders, in collaboration with the physician/APRN/PA, based on the known desires of the patient or, if unknown, the patient's best interests.

For information, clinical guidance resources or to obtain more forms, contact: TPOPP@practicalbioethics.org

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AND PROXY DECISION MAKERS AS NECESSARY FOR TREATMENT

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Kansas-Missouri TPOPP practicalbioethics.org

Section A

A. CHECK ONE	**CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing. If patient is not in cardiopulmonary arrest, follow orders in B and C.**
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Section B

B. CHECK ONE	INITIAL TREATMENT ORDERS: Follow these orders if patient has a pulse and/or is breathing.
	Reassess and discuss treatments with patient and/or representative regularly to ensure patients care goals are met.
	☐ **Full Treatments (required if CPR chosen in Section A).** **GOAL: Attempt to sustain life by all medically effective means.** Provide appropriate medical treatments as indicated in an attempt to prolong life, including intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion, including intensive care.
	☐ **Selective Treatments.** **GOAL: Attempt to restore functions while avoiding intensive care and resuscitation efforts (i.e., ventilator, defibrillation, and cardioversion).** May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.
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Section C

C. CHECK ONE	MEDICALLY ADMINISTERED NUTRITION: Offer food by mouth if desired by patient, is safe and tolerated.
	☐ Provide feeding through new or existing surgically-placed tubes ☐ Trial period for medically assisted nutrition but no surgically-placed tubes ☐ No medically assisted means of nutrition desired ☐ Not discussed or no decision made

Section D

D.	**ADDITIONAL ORDERS OR INSTRUCTIONS FOR SECTIONS B AND C:** Includes e.g., time trials, blood products, and other orders. [EMS Protocols may limit emergency responder ability to act on orders in this section.]

Section E

E. CHECK ALL THAT APPLY

INFORMATION AND SIGNATURES (E-Signed documents are valid)

Discussed with:

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TPOPP vs. Advance Healthcare Directive

TPOPP	AHCD
• For seriously ill/frail, at any age	• For anyone 18 and older
• Specific orders for ***current*** treatment	• General instructions for ***future*** treatment
• Can be signed by the decision-maker	• Appoints decision-maker

Thank you!

Maureen Dudgeon, M.D., M.A.

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