MISSOURI QUALITY INITIATIVE FOR NURSING HOMES (MOQI)

HEALTH CARE DECISION-MAKING AND ADVANCE DIRECTIVE POLICY

Sinclair School of Nursing
University of Missouri Health System

Last updated: January 28, 2015
Acknowledgement

The MOQI initiative acknowledges the work of key authors Keith Hampton, MSN, APRN, ACNS-BC; Katy Musterman, RN, MBA; Adrienne Holden, MSW, MPH, LMSW, ACSW; Charles Crecelius, MD, PhD; and Lori Popejoy, PhD, APRN, GCNS-BC.

Also acknowledged is the work of the Advance Directives Subcommittee for their critical advice and guidance: Colleen Galambos, PhD, LCSW-C, LCSW, ACSW, Chair; Lori Popejoy, PhD, APRN, GCNS-BC; Keith Hampton, MSN, ACNS-BC; Charles Crecelius, MD, PhD; Adrienne Holden, MSW, MPH, LMSW, ACSW; Brigid Fernandez, MSW, ESQ; Yvonne Schandt RN, BSN; Annette Lueckenotte, MSN, RN, FNGNA; Jan Doerr, MA, LBSW, CPG; Roger Schomburg; Michael Roth, BA, LNHA; Kayla Steinke, MSW; and Patty Abele, MSN, RN, FNP-BC.
## TABLE OF CONTENTS

I. Purpose Statement .................................................................................................................. 4

II. Policy Model .......................................................................................................................... 5

III. Definitions ............................................................................................................................. 6

IV. Policy ......................................................................................................................................... 8

V. Procedure .................................................................................................................................... 10
  Procedure Map - Flow Chart........................................................................................................ 10

VI. Decisional Capacity ................................................................................................................. 12
  Resident’s Lacking Decisional Capacity Who Have No Advance Directive ......................... 12
  Conflict Resolution .................................................................................................................. 12

VII. Example Conversation Table .................................................................................................. 13

VIII. Cardiopulmonary Resuscitation (CPR) Order Form ............................................................... 15

IX. Audit Tool and Documentation Checklist .................................................................................. 16
  Advance Directive Documentation Checklist............................................................................. 16
  Advance Directive Audit............................................................................................................. 17

X. INTERACT and Supporting Tools ............................................................................................... 20

XI. Resident Care Staff In-Service Examples .................................................................................. 28
  Facts and Myths of "Do Not Resuscitate" (DNR) (Crecelius, 2013) ........................................... 28
  Advance Directives and End-of-Life Decision Making - In-Service Outline/Key Points ....... 30

XII. Resources and Web Pages ........................................................................................................ 34


XIV. References ............................................................................................................................... 39
I. PURPOSE STATEMENT

It is vital that residents and representative/health care agents be involved in meaningful discussions about their health care status, and give the healthcare team direction as to how to proceed as their physical and/or cognitive function worsens. Health care planning, including advance care planning, is a person- or resident-centered approach that honors the preferences for care and treatment for those through the end of life.

The purpose of this policy is to provide guidance and procedures for documenting a resident’s health care planning, advanced directive, and end-of-life care preferences throughout the resident’s stay.
II. POLICY MODEL


The model for this policy/procedure provides guidance for assisting residents in long-term care to transition from curative disease-specific to palliative, comfort, and supportive care. With each transition of care, the resident’s goals of care can be evaluated using this model to determine the trajectory of the resident. Palliative care, meaning management of distressing symptoms, is intended to be given simultaneous to curative or disease management approaches. As this model demonstrates, as the resident’s condition deteriorates, palliative approaches become more of a focus of the care and treatment until the end of the life, where hospice care will be received.
III. **Definitions**

1. **Advance directive**: A legal document in which a person specifies what actions should or should not be taken regarding their health care when they are no longer able to make decisions for themselves due to incapacity or illness (The Missouri Bar, 2014).

2. **Artificial nutrition, hydration**: Nutrition and fluids delivered through a feeding tube or intravenous line (Office of Missouri Attorney General, 2009).

3. **Cardiopulmonary resuscitation (CPR)**: A medical procedure performed after the cessation of vital functions of the body including the heartbeat and breathing, that usually includes chest compression, the administration of drugs or electric shock to try to restore the heartbeat, and a tube placed in the windpipe for breathing (Brink, 2014).

4. **Durable power of attorney for finances**: A legal document that enables a person to appoint agent to manage their business and financial affairs, even if the person granting the authority becomes disabled, incapacitated or unable to communicate (The Missouri Bar, 2014).

5. **Durable power of attorney for healthcare**: A legal document that enables a person to appoint agent to make health care decisions and to follow a person’s choices, but only when that person is not able to make the decisions for him or herself. The Durable Power of Attorney remains in effect even when the person granting the authority becomes incapacitated or unable to communicate (The Missouri Bar, 2014).

6. **Legal guardian**: A person appointed by the court to have care and custody of a person who is unable to care for him or herself either for the person, property or both (The Missouri Bar, 2014).

7. **Health care provider**: A provider of healthcare services, who furnishes a bill or is paid for health care in the normal course of business; includes but not limited to physicians, osteopaths, psychiatrists, and advanced practice nurses (APRN).

8. **Health care agent**: The person authorized in the Health Care Directive or Durable Power of Attorney to make health decisions when the resident is not capable of making his or her own health care decisions.

9. **Hospice care**: A philosophy of care that focuses on relieving the symptoms of a person who is dying rather than trying to cure them, with care provided by a team of medical providers, counselors and volunteers (Office of Missouri Attorney General, 2009). Medical treatment may still be utilized to provide comfort to the dying person.

10. **Living will**: A declaration or statement that a person may make indicating the medical treatments that would like withheld or withdrawn and under certain circumstances when a person is near death (The Missouri Bar).

11. **Outside the hospital do-not-resuscitate**: The OHDNR is a physician’s order that the person will not be resuscitated if the person stops breathing or the person’s heart stops (The Missouri Bar, 2014).

12. **Palliative care/comfort care**: Care focused on providing persons or residents with relief of distressing symptoms such as pain, shortness of breath, or anxiety. The goal is to improve the quality of life for the resident and the family. This is care that prevents and relieves suffering and supports the best possible quality of life for residents and their families (Center for Advanced Palliative Care, 2014).

13. **Personal representative**: A person named in a will to administer the estate of the maker of the will (National Institute on Aging, 2014).
14. **Power of Attorney**: A document stating an individual has the authority to act on behalf of another person in regard to financial or business affairs (Office of Missouri Attorney General, 2009).

15. **Will**: A legal document in which a person states how they would like their estate distributed upon their death.
IV. Policy

1. Facility will form a clinical team who will be responsible to apply and monitor this policy, procedure, and education.

2. Each resident has the right to make decisions about his or her medical care. These decisions include:
   a. Cardiopulmonary Resuscitation, otherwise known as CPR
   b. Do not resuscitate, otherwise known as DNR, no code, or no CPR
   c. Artificial ventilation, otherwise known as a breathing machine, respirator or ventilator
   d. Artificial nutrition delivered through a tube, otherwise known as tube feeding
   e. Use of antibiotics
   f. Hospitalization
   g. Withdrawing or withholding medications

3. Each resident has the right to formulate an advance directive, or be offered the opportunity to do so.

4. Advance directives will be honored in compliance with federal or state laws and facility policy.

5. The resident that still has the capacity to make his or her own health care decisions may request not to be resuscitated or to have other life-sustaining measures withheld or withdrawn. The resident’s stated wishes supersede the written advance directive.

6. After receiving a new request for limitation of any treatment, the resident’s physician will be notified and an order requested for resident’s medical record
   a. Additionally, the representative/health care agent will be notified of the request and order.

7. During the admission process the facility will provide each resident with written information regarding his or her rights. The facility will ask if the resident has an advance directive, and if not, offer the resident with capacity the opportunity to complete an advance directive.

8. Additionally, the resident will be asked about his or her wishes/goals of care (Institutes of Medicine, 2014).
   a. To be rehabilitated
   b. To be able to perform activities of daily living
   c. To be provided palliative/comfort care

9. If the resident suffers worsening of state of his or her physical health, or change in condition that is not due to minor illness, and is most likely permanent, staff will initiate a discussion with the resident or his or her representative/health care agent about his or her goals of care and wishes for end-of-life care.
   a. A change of condition may include transfer and readmission from a healthcare facility, or a change in resident’s current state of health that does not include a transfer.

10. These discussions will be used to identify if previously stated goals are to remain the same or if the resident or representative/health care agent has a new preference (e.g. comfort care, hospice, DNR).

11. Discussions about CPR are to take place on the first day the resident has been admitted to the facility (CMS F156, 2014). A meeting to discuss health care planning and end-of-life
preferences will occur within two weeks of admission, with health care personnel qualified to discuss with the resident and family/significant other issues pertinent to his or her circumstances.

12. If the resident unexpectedly dies, or is in the process of dying and no preference for end of life decisions, including CPR have been documented, CPR will be attempted.

13. An Out-of-Hospital Do Not Resuscitate Order Form (OHDNR) may be used as an alternative to a physician/provider order for DNR ordering purposes.
V. **Procedure**

**Procedure Map - Flow Chart**

**Health Care Decision Making and Advance Directive**

1. **On Admission** - During the admission process, the admission office personnel, admitting nurse or social worker will give each resident or representative/health care agent information about advance directives, ask if an advance directive has been executed, request a copy of the advance directive, and discuss the resident’s wishes related to CPR. Facility policy and procedure will be explained by the admitting personnel.

2. **Health Care Decision Making Discussions** (see V. Procedure Map above)

3. **Quarterly and Annual Assessment** - Advance directives will be reviewed and discussed at the quarterly care plan conference with an annual overall review of resident’s goals of care and advance directive status.

4. **Change of Condition** - When a significant change of condition occurs that is most likely a permanent change, the resident’s previously stated preferences will be reviewed with the resident/representative/health care agent and health care provider.

5. **Transition of Care** - Advance directives will be reviewed and discussed with each physical or medical transition of care.

6. **Change in Goals of Care** - If the resident/representative/health care agent begins a discussion about wishing to change his or her goals of care, documentation of the discussion will be placed in the new resident’s wishes in the resident’s medical record.
7. The resident has the right to revoke the advance directive at any time and to request treatments that were previously refused.
8. If the resident is unable to participate in this discussion following a change of condition or at a care plan conference, the discussion will be held with the representative/health care agent.
9. All health care providers should follow the documented wishes of the resident, and discuss these wishes with the representative/health care agent appointed through a durable power of attorney for health. If a provider no longer concurs with the resident’s previously stated wishes, a meeting will be held with all involved parties and facility leadership, to include, but not limited to, the facility administrator, director of nursing, social worker, and ombudsman.
10. The social worker will also document which advance directive documents (e.g. living will, durable power of attorney for health care) were submitted by the resident or representative/health care agent.
11. The facility will document in the resident’s health care record that the advance directive has been reviewed with the resident/representative/health care agent. A copy of the advance directive will be placed in a designated location in the resident’s medical record and in the resident’s financial file in the facility’s business office.
12. Staff Education
   a. New staff/ongoing education will include information about:
      i. Individual goals of care
      ii. Advance directives
      iii. Code status
      iv. Hospice and palliative care
   b. Annual Re-Training - Annually staff will receive updating education related to:
      i. Individuals’ goals of care
      ii. Hospice and palliative care
      iii. Code status
      iv. Advance directives
   c. In-services:
      i. Policy/procedure review
      ii. Goals of care
      iii. Hospice
      iv. Palliative care
      v. DNR
      vi. Advance directives
VI. DECISIONAL CAPACITY

Persons are presumed to have capacity to manage his or her own affairs unless there has been a legal or medical determination of incapacity or disability. Persons may be determined to lack capacity to handle his or her finances, but have capacity to make his or her health care wishes known.

RESIDENT’S LACKING DECISIONAL CAPACITY WHO HAVE NO ADVANCE DIRECTIVE

1. If a resident is or becomes incapable of making treatment decisions before conveying his or her wishes regarding the use of cardiopulmonary resuscitation (CPR) or other life sustaining measures and there is no legal guardian or health care agent, the family may serve as the designated representative/health care agent.
2. Where there is no guardian and no appropriate surrogate decision maker for the resident who lacks decision-making capacity, the nursing home may consider seeking a legal guardianship.
3. If the prior wishes of a resident regarding the use of life-sustaining measures cannot be identified, and there is no designated representative/health care agent to make decisions on behalf of the resident, life-sustaining measures will be provided; unless within the reasonable medical judgment of the healthcare provider, measures are clearly more burdensome than beneficial to the resident.

CONFLICT RESOLUTION

1. If there are questions or concerns regarding the decisional capacity of the resident, or a disagreement occurs among the representative/health care agent or the health care provider about the appropriateness of the directives, a meeting will be held with all involved parties to resolve the dilemma. This meeting may include an ombudsman.
2. If unresolved questions or lack of consensus remains regarding the decisional capacity of the resident or the appropriateness of the directives, the facility ethics committee or board will be consulted. The ombudsman will also be contacted. Recommendations from the ethics committee or board will be advisory in nature. The discussion with the ethics committee or board members may help clarify the issues and resolve the dispute. The ethics committee or board can be called for an emergency meeting for this purpose. If the facility does not have an ethics committee, the medical director, consulting psychiatrist, attending physician, and director of nursing and lead social worker or director of social services will convene as an ad hoc committee to address the decision that is in conflict.
3. If conflicts arise among the designated representative/health care agent and the health care provider or facility regarding the initiation of certain requests, and the issues cannot be resolved, the resident and family have the right to consult another health care provider, or to seek other living arrangements.
4. The wishes of a resident with decisional capacity are honored over the wishes of other interested parties.
### VII. Example Conversation Table

<table>
<thead>
<tr>
<th>STEPS</th>
<th>DOMAIN OF CARE</th>
</tr>
</thead>
</table>
| 1) Introduce the topic | **Values**  
*Health care provider:* As my patients get older, I need to better understand their values and goals for health care if they get too sick to make decisions or choices on their own. Can we talk for a minute about what you consider important goals for me to know if you become critically ill? |
| | **Living Will**  
*Health care provider:* Have you thought about the type of medical care you would like to have if you ever become too sick to speak for yourself? |
| | **Health Care Proxy**  
*Health care provider:* If you were not able to speak for yourself, who would be best to represent your views and values? |
| 2) Engage in the discussion about goals of care and future planning | **Values and Goals**  
*Health care provider:* Given the severity of your illness, what is most important for you to achieve? How do you think about balancing quality of life with the length of life in terms of your treatment? What are you most important hopes? What are your biggest fears? |
| | **Medical Decisions**  
*Health care provider:* Imagine you were to have an accident or illness, which caused you to be unable to communicate, like a coma, and we were unsure if you will regain consciousness. Your family and I need to know how you would want us to care for you. Some people choose to withdraw treatment and let them die, others want us to do everything we can to maintain life, do you have any thoughts about how you would want us to proceed? What if at the time you also had a diagnosis of dementia or Alzheimer’s and were in this situation? |
| | **Social support**  
*Health care provider:* Have you thought about who might be able to care for you should you become unable to care for yourself? For instance, if you were unable to do your own bathing, or become confined to bed, or are unable to cook for yourself, do you have someone who can care for you at home? Have you and your friends/family discussed where you might choose to live as you get older and less able to manage your activities such as bathing, preparing your meals, managing your money? |
### Financial

*Health care provider:* Is there someone among your family/friends who understands your financial situation, such as your insurance or ability to pay for extra help at home in case you are too ill or unable to understand these things?

### Prioritizing goals

*Health care provider:* Can you help me understand what is most important to you now that you have a life limiting illness that you will not get better from? How would you rank the following in importance? Is it more important to you that we extend your life as long as possible, maintain your consciousness and physical function as long as we can, or keep you as comfortable as possible?

*Health care provider:* Thanks for helping me understand what matters to you. I would like to write these things down in your medical record and then review them with you in the future. In addition, it would be wise for you to document them formally in something called an advance directive. If you like, I can also refer you to someone who can assist you with that process.

### Social support

*Health care provider:* When we talked several years ago you said that if the day came that I felt you were not safe in your own home you would be willing to make some changes, I think we need to discuss that now.

### Medical decisions

*Health care provider:* If you were to die suddenly, that is, you stopped breathing or your heart stopped, we could try to revive you by using cardiopulmonary resuscitation. Are you familiar with CPR? Have you given thought as to whether you would want it?

*Health care provider to family:* As you know, your mother has previously asked that you serve as her proxy if she could not make decisions for herself. I would just like you to know that in our discussions over the years, she was clear that she did not want extreme measures to prolong her life, rather she valued comfort above all else. Is this consistent with your understanding?

*Health care provider to family:* Given the severity of your mother’s illness, CPR would likely be ineffective. I would recommend that we choose to not attempt it, but that we continue all potentially effective treatments. What do you think?

(Zweig, Popejoy, Parker-Oliver, & Meadows, 2011)
VIII. CARDIOPULMONARY RESUSCITATION (CPR) ORDER FORM

Cardiopulmonary Resuscitation is only used after death has occurred, or there are no discernable signs of life; the heart has stopped beating, no pulse can be found, and/or the individual has stopped breathing, or both.

CPR is administered by trained staff. Any person trained in CPR may perform it, but you can expect that a Registered Nurse or a Licensed Practical Nurse will assume care and deliver CPR by applying force to your chest with his or her hand (chest compressions), and breathing into your mouth to fill your lungs with air. CPR is done to attempt to make your heart start beating again.

For older adults living in long-term care facilities that receive CPR, the overall success rate is 3% (Brink, 2014). The chances of returning to your present state of function are between 0% and 5% for a long-term care facility resident (Zweig, 1997).

Without a DNR order in place, medical staff is required by law to begin CPR, even if rigor mortis has set in. Rigor mortis is stiffness of the body that occurs 2-6 hours after death has taken place due to chemical changes in the body.

Anytime CPR is performed, emergency assistance or 911 is called. When the paramedics arrive, they will take over your care. Based upon your status, the paramedics may need to place a tube into your throat to help you breath, shock your heart, and/or give you medications in an effort to attempt to stabilize your medical condition.

If you are able to be resuscitated, you will be transferred to a hospital for further treatment which may include being on a ventilator, being fed through a feeding tube, and undergoing dialysis. As with any medical procedure, CPR has risks. Your ribs could be broken and your lungs be punctured. If too much time elapses while you are without oxygen (3 to 10 minutes) you could experience brain damage and brain death.

If you choose not to receive CPR an order will be written for do not resuscitate (DNR). DNR is sometimes referred to allowing natural death. You will continue to receive care and medical treatment for health care conditions. DNR only applies to the use of CPR.

Please consider the information above and the wishes of you and your family. Please indicate your preference for resuscitation by checking next to one of these statements:

[ ] I do wish for CPR to be performed
[ ] I do not wish to have CPR performed and wish to be a DNR

Name of Resident (Printed)  Signature or Resident or Responsible Party

[ ] Date
## IX. Audit Tool and Documentation Checklist

### Advance Directive Documentation Checklist

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Document the existence of a valid advance directive in the resident’s medical record. Note date document executed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtain a copy of the advance directive and insert it in the resident’s medical record.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Document in a readily apparent location the name, telephone number, and address of designated representative(s) and alternate agent(s).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtain physician’s order for any specific requests for treatment or non-treatment (e.g. do not resuscitate).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Document in the resident’s record that the specific order was received, along with any pertinent related discussions with the physician or provider.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Document the content of discussion(s) with the resident and/or designated representative(s) regarding advance directives or requests to withhold or withdraw treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Document treatment preferences not expressed in advance directive documents. Encourage resident to include these in advance directive and to inform designated representative.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place INTERACT Advance Care Planning Tracking Form in resident’s record with the date the advance directive was obtained.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Record on the 24-hour report sheet that an advance directive was obtained.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review the advance directive at the resident’s quarterly care plan or as indicated due to a change in the resident’s condition or preferences. Take follow up action as indicated.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ADVANCE DIRECTIVE AUDIT

Audit Objectives:
1. To evaluate compliance with advance directive documentation policies and procedures.
2. To identify any areas of deficiency and/or concern in compliance with advance directive documentation practices.
3. To propose revisions in advance directive documentation policies and procedures to improve compliance with related documentation practices.

Sample: All residents of the facility with advance directives.

Audit Study Size: All residents of the facility who are known to have advance directives during the designated time period.

Time Period of Evaluation: From: ____________ to: ____________

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Exceptions</th>
<th>Instructions for Data Retrieval</th>
<th>Present</th>
<th>Absent</th>
<th>N/A</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>The existence of a valid advance directive, including date document was executed, is documented in medical record</td>
<td>None</td>
<td>clinical record</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A copy of advance directive is in the medical record</td>
<td>None</td>
<td>clinical record</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The resident’s records contains an INTERACT Advance Care Planning Tracking Form with the date indicating when the advance directive was obtained</td>
<td>None</td>
<td>clinical record</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The names, telephone numbers, and alternate agents are documented on the face sheet</td>
<td>None</td>
<td>face sheet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A physician’s order for specific treatment or non-treatment requests is on the Monthly Physician’s Order Sheet</td>
<td>None</td>
<td>monthly physician’s order sheet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The physician’s order specifies explicitly what will or will not be done for the resident (e.g. Do Not Resuscitate)</td>
<td>None</td>
<td>monthly physician’s order sheet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The following documentation is included in the resident’s record</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The specific physician's order and any pertinent related discussions with the physician/provider are recorded</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>------</td>
<td>-----------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b.</td>
<td>Discussions with the resident pertaining to advance directives or requests to withhold or withdraw treatment are recorded</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c.</td>
<td>Discussion with designated representative(s) regarding advance directives are recorded</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d.</td>
<td>Treatment preferences not expressed in advance directive documents are recorded</td>
<td>No other preference expressed</td>
<td>No other preference expressed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.</td>
<td>Evidence that the resident was encouraged to include specific treatment preferences in advance directive and to inform designated representatives is recorded</td>
<td>No other preference expressed</td>
<td>No other preference expressed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f.</td>
<td>The discussion(s) with the resident includes signature(s) of the staff involved</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g.</td>
<td>The discussion(s) with the designated representative includes the signature(s) of the staff involved</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h.</td>
<td>The discussion with the resident includes the resident’s signature, when possible. If the resident does not sign the form, a notation is made explaining why it was not appropriate or possible for the resident to sign</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i.</td>
<td>The resident’s designated representative signatures are recorded, when possible. If not, a notation is made explaining why is was not appropriate or possible for the resident or representative to sign</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. The record contains documentation of all subsequent discussions among licensed staff, family, or designated representatives, the resident, or the physician/provider concerning advance directives</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>k. The record includes documentation of the review of the advance directive and specific treatment or non-treatment orders with the physician/provider, the resident, and the family or designated representative at time of significant changes in condition, when, applicable</td>
<td>No significant change in condition</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I. The record includes documentation of the review of the advance directive by the care planning team</td>
<td>None</td>
<td>Clinical record</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>J. The Nursing Care Plan contains evidence that the resident's advance directive is reviewed quarterly</td>
<td>None</td>
<td>Nursing Care Plan</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>k. The Nursing Care Plan is signed by participants in the care plan meeting.</td>
<td>None</td>
<td>Nursing Care Plan</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### X. INTERACT AND SUPPORTING TOOLS

<table>
<thead>
<tr>
<th>INTERACT Tool</th>
<th>Hyperlink</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify Residents who may be Appropriate for Hospice or Palliative-Comfort Care Orders</td>
<td><a href="http://interact2.net/tools_v3.aspx">http://interact2.net/tools_v3.aspx</a></td>
</tr>
<tr>
<td>Comfort Care Interventions - Examples</td>
<td><a href="http://interact2.net/tools_v3.aspx">http://interact2.net/tools_v3.aspx</a></td>
</tr>
<tr>
<td>Advance Care Planning Tracking Form</td>
<td><a href="http://interact2.net/tools_v3.aspx">http://interact2.net/tools_v3.aspx</a></td>
</tr>
<tr>
<td>Advance Care Planning Tracking Form - Continuation Page</td>
<td><a href="http://interact2.net/tools_v3.aspx">http://interact2.net/tools_v3.aspx</a></td>
</tr>
</tbody>
</table>
Advance Care Planning
Communication Guide: Overview

The INTERACT Advance Care Planning Communication Guide is designed to assist health professionals who work in nursing homes to initiate and carry out conversations with residents and their families about goals of care and preferences at the time of admission, at regular intervals, and when there has been a decline in health status.

The Guide can be useful for education, including role-playing exercises and simulation training.

Communicating about advance care planning and end-of-life care involves all facility staff

- Physicians must communicate with residents and families about advance directives, but all staff need to be able to communicate about goals of care, preferences, and end-of-life care

This Guide should therefore be useful for:

- Nursing staff
- Primary care physicians, nurse practitioners, and physician assistants
- Social workers and social work designees
- Administrators and others who discuss goals of care with residents and family

The Guide may be helpful in discussions on:

- Advance Directives – such as a Durable Power of Attorney for Health Care document, Living Will, and POLST and other similar directives
- Plans for care when a sudden, life-threatening condition is diagnosed – such as a stroke, heart attack, pneumonia, or cancer
- Plans for care when a resident's health is gradually deteriorating – such as progression of Alzheimer's disease or other dementia; weight loss without an obvious medical cause; and worsening of congestive heart failure, kidney failure, or chronic lung disease
- Considering a palliative or comfort care plan or enrolling in a hospice program
Identifying Residents who may be Appropriate for Hospice or Palliative/Comfort Care Orders

I. Residents with Selected Diagnoses who may be Appropriate for Hospice

Congestive Heart Failure
- Symptoms of CHF at rest (New York Heart Association class IV)
- Serum sodium level < 134 mmol/L or creatinine level > 2.0 mg/dL due to poor cardiac output
- Intensive care unit admission for exacerbation

Chronic Obstructive Pulmonary Disease
- Cor pulmonale (right-sided heart failure associated with COPD)
- Intensive care unit admission for exacerbation
- New dependence in two activities of daily living (ADLs) due to COPD symptoms
- Chronic hypercapnia (PaCO2 > 50 mm Hg)

Dementia
- Dependence in all ADLs, language limited to just a few words, and inability to ambulate
- Acute hospitalization (especially for pneumonia or hip fracture)
- Difficulty swallowing with recurrent aspiration
- Has feeding tube due to dementia or swallowing difficulty related to dementia

Cancer
- Poor physical performance status as a result of cancer (dependence in multiple ADLs)
- Multiple tumor sites
- Metastatic cancer involving liver or brain
- Bowel obstruction due to cancer
- Pericardial effusion due to cancer

II. Residents at High Risk of Actively Dying who Should be Considered for Palliative or Comfort Care Orders (if not already on Hospice)

- Frequent Emergency Room visits and/or hospitalizations over the last 6 months
- Sudden, major decline in functional status with no identified reversible causes
- Primary diagnosis of metastatic cancer with chronic pain and/or poor ADL function, not on chemotherapy
- Semi-comatose or comatose state with no identified reversible causes
- Inability or difficulty taking oral medicines
- Minimal oral intake (or receiving continuous or intermittent IV hydration)
- Mottling of extremities related to poor oral intake or volume depletion

©2011 Florida Atlantic University, all rights reserved. This document is available for clinical use, but may not be reused or incorporated in software without permission of Florida Atlantic University.
Comfort Care Interventions

Examples

Some nursing home residents and/or their families are reluctant to enroll in hospice but would like a comfort care plan. The examples of comfort care orders below may be helpful for these residents, who will not have hospice order sets.

<table>
<thead>
<tr>
<th>Order Type</th>
<th>Examples and Helpful Tips</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>1. Order a diet <em>(it may improve the desire to taste food)</em></td>
</tr>
<tr>
<td></td>
<td>2. Full rather than clear liquid if liquid diet necessary</td>
</tr>
<tr>
<td></td>
<td>3. May have food brought in by family</td>
</tr>
<tr>
<td></td>
<td>4. Allow resident to sit up for meals</td>
</tr>
<tr>
<td>Activity</td>
<td>1. Allow resident to sit in chair and use a bedside commode if capable and desired</td>
</tr>
<tr>
<td></td>
<td>2. Other activities as tolerated</td>
</tr>
<tr>
<td></td>
<td>3. Allow family to stay in room</td>
</tr>
<tr>
<td>Vital Signs</td>
<td>1. Minimum frequency allowed by policy</td>
</tr>
<tr>
<td></td>
<td>a. Frequent monitoring and numbers can alarm resident and family</td>
</tr>
<tr>
<td></td>
<td>b. Limit MD/NP/PA notification parameters</td>
</tr>
<tr>
<td>IV Orders</td>
<td>1. If IV fluids are needed, use a time limited trial, <em>(e.g. 1000cc of D5 ½ Normal Saline over 6 hrs)</em></td>
</tr>
<tr>
<td></td>
<td>a. Starting IV is often difficult and painful – and usually of limited benefit</td>
</tr>
<tr>
<td></td>
<td>2. Subcutaneous injections of small volumes of medicines using a small butterfly needle</td>
</tr>
<tr>
<td></td>
<td>under the skin of the thigh or abdomen may avoid the need for IV therapy</td>
</tr>
<tr>
<td>Orders for Dyspnea</td>
<td>1. Oxygen 2 - 4 L by nasal cannula; avoid mask if possible</td>
</tr>
<tr>
<td>and Shortness of</td>
<td>2. Avoid monitoring oxygen saturations</td>
</tr>
<tr>
<td>Breath</td>
<td>3. Blow air on face with a bedside fan or open window</td>
</tr>
<tr>
<td></td>
<td>4. Nebulizers may be helpful</td>
</tr>
<tr>
<td></td>
<td>5. Consider steroids if wheezing present</td>
</tr>
<tr>
<td></td>
<td>6. Use opioids for persistent dyspnea</td>
</tr>
<tr>
<td></td>
<td>7. Use antibiotics if a bacterial infection is exacerbating dyspnea and treatment may</td>
</tr>
<tr>
<td></td>
<td>improve symptoms</td>
</tr>
<tr>
<td>Hygiene</td>
<td>1. Avoid bladder (Foley) catheter if possible</td>
</tr>
<tr>
<td></td>
<td>a. May be helpful in selected residents who are immobile and have pain with toileting</td>
</tr>
<tr>
<td></td>
<td>or movement</td>
</tr>
<tr>
<td></td>
<td>2. Check regularly for stool impaction</td>
</tr>
<tr>
<td></td>
<td>a. Suppositories may be helpful</td>
</tr>
<tr>
<td></td>
<td>3. Monitor for oral thrush</td>
</tr>
<tr>
<td></td>
<td>4. Petroleum jelly to lips may be helpful for dry mouth</td>
</tr>
<tr>
<td></td>
<td>5. Allow family to cleanse mouth with sponge sticks</td>
</tr>
</tbody>
</table>
## Comfort Care Interventions

### Examples (cont’d)

<table>
<thead>
<tr>
<th>Order Type</th>
<th>Examples and Helpful Tips</th>
</tr>
</thead>
</table>
| Pain and Dyspnea                  | 1. Opioids usually most effective  
2. Use small, frequent doses as needed for opioid-naive residents  
3. Consider stopping sustained preparations and switching to immediate release Morphine concentrate 20 mg/ml  
4. Start with equivalent dose as previous regimen – at least 5 mg PO every 2 hrs  
5. Offer routinely, and let the resident refuse  
6. Use short-acting benzodiazepine if anxiety is present                                                                                     |
| Anorexia, Asthenia, Fatigue, Depression, Pain, Dyspnea | 1. Corticosteroids can have beneficial effects  
a. Use Dexamethasone 4 - 8 mg PO or subcutaneous at breakfast and lunch  
   (avoids the mineralocorticoid effects of Prednisone)  
b. Employ sleep hygiene measures to facilitate optimal nighttime sleep                                                                 |
| Nausea and Delirium               | 1. Review underlying cause(s) of delirium and nausea, and eliminate if possible  
2. Haloperidol 0.25 - 2 mg PO or 0.5 - 1 mg subcutaneous every 2 hrs for 3 doses or until symptoms relieved, then every 4 hours PRN                                                                 |
| Anxiety and Seizures              | 1. Lorazepam for anxiety 0.5 - 2 mg PO or subcutaneous every 6 - 8 hrs  
a. Must be given IV or subcutaneous for seizures                                                                                                 |
| Sleep                             | 1. Trazodone 25 - 100 mg PO or Zolpidem 5 - 10 mg PO qhs                                                                                                                                                    |
| Skin, Pruritus, Wounds            | 1. Keep skin moist; use moisturizing soap or lotions  
2. Hydrocortisone creams may be helpful  
3. Benadryl 25 - 50 mg PO every 4 hours for pruritus  
4. Lidocaine 2% gel PRN to painful wounds                                                                                                           |
| ‘Death Rattle’                    | 1. Keep back of throat dry by turning head to the side  
2. Stop IV fluids or tube feedings  
3. Use a Scopolamine patch; Atropine drops 2 - 3 in the mouth every 4 hrs until patch is effective  
a. Use glycopyrrrolate, 1 - 2 mg PO or 0.1 - 0.2 mg IV or subcutaneous every 4 hrs;  
   or 0.4 - 1.2 mg/day continuous infusion is an alternative  
5. Avoid deep suctioning  
6. Allow family to cleanse mouth with sponge sticks                                                                                               |
| Comfort, Counseling, Safety       | 1. Sit with resident and talk to avoid isolation  
2. Reposition and massage regularly  
3. Avoid sensory overload (e.g. loud TV); use soft music  
4. Avoid use of restraints, bedrails, and alarms  
5. Religious counseling should be considered if acceptable                                                                                      |
Advance Care Planning
Tracking Form

Resident Name

Residents and/or their responsible health care decision makers should be provided the opportunity to discuss advance care planning with appropriate staff members and medical providers within the first few days of admission to the facility, at times of change in condition, and periodically for routine updating of care plans. The purpose of this form is to provide a tool to document that these discussions are taking place.

At Admission (within about a week of admission or readmission)
Check one of the following:
☐ Resident and/or responsible party did NOT want to have this discussion
☐ Discussion about advance care planning held with (check one or both of the following):

Resident
Resident’s surrogate; name:

Staff or healthcare provider completing form:
Name: ____________________ Title: ____________________
Signature: ____________________ Date of discussion __________ / __________ / __________

Location of Advance Care Plan documentation (i.e. advance directive tab, plan of care, progress notes, etc…):

____________________________
____________________________
____________________________

Use Continuation Pages to document additional Advance Care Planning Reviews and Discussions
Advance Care Planning Tracking Form
Continuation Page (copy as needed)

Advance Care Plan Review and/or Discussion
Purpose of Review:
☐ Care Planning (routine update)
☐ Change in Condition
☐ Other (specify) __________________________

If discussion was held, with whom (check all that apply):
Resident __________________________________
Resident’s surrogate; name: ______________________
No discussion held

Was a change in advance care plan or advance directive made? ☐ No ☐ Yes (describe) __________________________

Staff or healthcare provider leading discussion:
Name __________________________ Title __________________________
Signature __________________________ Date of discussion ______/____/____

Advance Care Plan Review and/or Discussion
Purpose of Review:
☐ Care Planning (routine update)
☐ Change in Condition
☐ Other (specify) __________________________

If discussion was held, with whom (check all that apply):
Resident __________________________________
Resident’s surrogate; name: ______________________
No discussion held

Was a change in advance care plan or advance directive made? ☐ No ☐ Yes (describe) __________________________

Staff or healthcare provider leading discussion:
Name __________________________ Title __________________________
Signature __________________________ Date of discussion ______/____/____

This form was adapted from the Advancing Excellence in America’s Nursing Homes website.

©2017 Florida Atlantic University; all rights reserved. This document is available for clinical use, but may not be resold or incorporated in software without permission of Florida Atlantic University.

© MISSOURI QUALITY INITIATIVE FOR NURSING HOMES (MOQI), UNIVERSITY OF MISSOURI, 2015
OUTSIDE THE HOSPITAL DO-NOT-RESCUCITATE (OHDRN) ORDER

I, ________________________, authorize emergency medical services personnel to withhold or withdraw cardiopulmonary resuscitation from me in the event I suffer cardiac or respiratory arrest. Cardiac arrest means my heart stops beating and respiratory arrest means I stop breathing.

I understand that in the event that I suffer cardiac or respiratory arrest, this OHDRN order will take effect and no medical procedure to restart breathing or heart functioning will be instituted.

I understand this decision will not prevent me from obtaining other emergency medical care and medical interventions, such as intravenous fluids, oxygen or therapies other than cardiopulmonary resuscitation such as those deemed necessary to provide comfort care or to alleviate pain by any health care provider (e.g., paramedics) and/or medical care directed by a physician prior to my death.

I understand I may revoke this order at any time.

I give permission for this OHDRN order to be given to outside the hospital care providers (e.g., paramedics), doctors, nurses, or other health care personnel as necessary to implement this order.

I hereby agree to the “Outside The Hospital Do-Not-Resuscitate” (OHDRN) Order.

<table>
<thead>
<tr>
<th>Patient – Printed or Typed Name</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s Signature or Patient Representative’s Signature</td>
<td>Date</td>
</tr>
</tbody>
</table>

REVOCAUTION PROVISION

I hereby revoke the above declaration.

| Patient’s Signature or Patient Representative’s Signature | Date |

I AUTHORIZE EMERGENCY MEDICAL SERVICES PERSONNEL TO WITHHOLD OR WITHDRAW CARDIOPULMONARY RESUSCITATION FROM THE PATIENT IN THE EVENT OF CARDIAC OR RESPIRATORY ARREST.

I affirm this order is the expressed wish of the patient/patient’s representative, medically appropriate and documented in the patient’s permanent medical record.

<table>
<thead>
<tr>
<th>Attending Physician’s Signature (Mandatory)</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending Physician – Printed or Typed Name</td>
<td>Attending Physician’s License No.</td>
</tr>
<tr>
<td>Address – Printed or Typed</td>
<td>Facility or Agency Name</td>
</tr>
</tbody>
</table>

THIS OHDRN ORDER SHALL REMAIN WITH THE PATIENT WHEN TRANSFERRED OUTSIDE THE HEALTH CARE FACILITY.

Emergency Medical Services personnel shall not comply with an outside the hospital do-not-resuscitate order when the patient or the patient’s representative expresses to such personnel in any manner, before or after the onset of a cardiac or respiratory arrest, the desire to be resuscitated or if the patient is or is believed to be pregnant.

Statutory citation 190.600-190.621 RSMo
9/07
XI. Resident Care Staff In-Service Examples

**Facts and Myths of "Do Not Resuscitate" (DNR) (Crecelius, 2013)**

"Do Not Resuscitate" (DNR) is a term used to indicate that when a person is found to be in the active dying process that we will provide comfort measures and let them pass naturally, as opposed to performing CPR (cardiopulmonary resuscitation). There are many facts and myths regarding CPR and DNR orders that need to be clarified in order to help you make the best decision for yourself and your loved ones. DNR should be taken very seriously and with appropriate thought to the risks, benefits and the appropriateness to the person involved.

**MYTH: DNR equals "Do Not Care"

**FACTS:** Nothing could be further from the truth. DNR is simply not doing a medical procedure that was originally designed for younger patients in their 50s and 60s having an acute myocardial infarction (heart attack). A DNR order in a nursing home means absolutely everything will be done up to the point that the patient is found to be in the active dying process. Labs will be done. Antibiotics will be ordered. Tests will be performed. Patients will go to the hospital. 911 can be called, and any and all other measures can be entertained. If the person or patient wants more specific orders to indicate they want "comfort measures only," such as "Do Not Hospitalize," "Do Not Give IV Antibiotics," etc., these must be individually specified and have absolutely nothing to do with a DNR order. DNR pertains ONLY to the active dying process and not to any other stage.

**MYTH: DNR is usually successful

**FACTS:** DNR is usually unsuccessful in nursing home patients. A well-recognized medical journal noted that on TV shows, CPR is successful half the time. Nothing could be further from the truth. In younger people, DNR at best is successful one-fourth of the time under ideal conditions.
circumstances. In older patients residing in nursing homes, studies have shown there is only a 3 percent overall success rate. Many of these people are much more impaired after they return from the hospital. CPR is considered by many medical authorities to be essentially futile. It is, however, a personal decision and the right of the individual to request it.

**MYTH:** CPR can’t hurt

**FACTS:** CPR is an aggressive medical measure in which the chest is compressed upon vigorously. Frail older patients usually have multiple rib fractures from this procedure. This normally results in people being left on ventilators for long periods of time due to severe chest pain and inability to breathe on their own, during which time they often develop pneumonias and other medical complications. This is one of many reasons why CPR is not usually successful in older patients. The patients are often semi-awake during the procedure and may be very aware of chest compressions and ribs being broken, and may sustain relatively severe pain. Being on a ventilator is not a pleasant experience, especially for people with cognitive impairment who can be extremely frightened, more confused, and in frightful distress during their time in the Intensive Care Unit in the hospital. Doctors take the Hippocratic Oath to "do no harm." seriously. CPR on the wrong person unfortunately usually causes far more harm than any potential good. Medical Records Newsletter,

**MYTH:** "Doing everything" means we need to do CPR

**FACTS:** Again, nothing could be further from the truth. "Doing everything," means doing everything that is right for that patient at that time. At different times in a patient’s life, different medical interventions are appropriate. It would be rare to find a 60-year-old person who should not undergo bypass surgery. However, it would be rare to find a 90-year-old person with dementia for whom it would be appropriate to undergo major bypass surgery. Similarly, doing CPR on a very old person with osteoporosis, heart disease, who has had strokes or other serious diseases, is often very medically inappropriate. It is more akin to doing the wrong thing than doing "everything." It may be difficult to make these decisions, but more often "doing everything" means keeping the person comfortable, having more concern for their everyday quality of life, and providing for their daily emotional and physical comfort; rather than doing aggressive measures that can cause harm, make their last days on this earth painful and mentally agonizing, and not allow them to have the peaceful death that most people would want.

**FACT:** We must do what the patient wants

**FACTS:** As a medical doctor, I often find that families are torn about what to do when it comes to a DNR order. I will usually ask the family, "If your loved one had been able to look into a crystal ball 30 years ago and could have seen his or her current life and condition, what would he or she have wanted done?" More often than not, when this perspective is taken, families will realize that their loved one would not have wanted to undergo aggressive measures at this stage in their life. Instead they often realize their loved one would have wanted to be allowed to have a natural death rather than to undergo aggressive measures with limited ability to help and even greater potential to harm. Many older people did not express exact wishes. Sometimes they may have known a relative who underwent medical procedures and went
through a painful death, and may have noted that they would not want that to happen to them. This is tantamount to expressing their wishes.

For children it is especially difficult to make a DNR order. You may feel you are abandoning your parent or not providing him or her with every opportunity of life. As responsible parties, you have a moral obligation to do both what your parents would have wanted and what is in their best medical interests. I would invite you to speak to your health care provider and have a meaningful discussion regarding your loved one’s prognoses and the ability of CPR to be successful. In this way, you can come to both an intelligent and a correct ethical decision regarding DNR. DNR is about doing the right thing medically and morally. It is not about giving up.

**ADVANCE DIRECTIVES AND END-OF-LIFE DECISION MAKING - IN-SERVICE OUTLINE/KEY POINTS**

**Purpose**
- Discuss advance directives and end-of-life care decisions
- Learn the different types of advance directives
- Recognize advantages and disadvantages of advance directives
- Identify resources that can be used to complete advance directives

Does your resident have a written plan stating what health care treatments you would or would not want if he/she could not speak for him/herself?

Why Bother? (Use a photo and story as an example, or add your own slide and story as appropriate)

Victor is a married business executive whose best friend was in a coma from a critical car accident. After his friend was in the intensive care unit for 4 weeks, he was diagnosed as “brain dead.” Victor witnessed the agonizing and difficult decisions his friend’s family had to make about whether to continue life-sustaining treatments or not.

Victor’s friend had never talked about his end-of-life care wishes and had not completed his advance directives which left his family in a major crisis about what decisions to make. Victor knew that if he were in the same situation, he would not want to be kept alive on a ventilator and feeding tubes.

Victor talked to his wife about what he would want if he were ever in a similar situation and completed his advance directives. Victor also discussed his advance directives with his primary doctor and gave him a copy to include in his medical records.

Since Victor has talked about what health care he wants and does not want with his wife and doctor, he can now trust that his end-of-life care wishes will be honored.

Victor’s example is one of many that highlight the need for all of us to think through and make a plan about our care at the end of life.

**Why You Need Advance Directives**
- Your wishes will be known
- Only used if you are unable to express your decisions
- This can happen to anyone - at any age
- Give your loved ones the gift of peace of mind - write down your wishes!
Interesting to note...

- Most Americans - 88% - feel comfortable discussing issues relating to death and dying
- *Yet only 42% have a living will*

What are **Advance Directives**?

- A written statement of a resident’s wishes, preferences and choices regarding end-of-life health care decisions
- A tool to help residents think through and communicate their choices

*Note: Each state regulates the use of advance directives differently*

Generally advance directives are:

- Oral and written instructions about future medical care
- Only used if you are seriously ill or injured AND unable to speak for yourself

Two documents that make up an advance directives:

- Living will
- Medical power of attorney

Your right to accept or refuse treatment is protected by constitutional and common law through a **living will**.

A **living will** is a legal document with your wishes about medical treatment.

You can choose what treatments you want and do not want.

**Medical power of attorney** can be used at any time - not only at the end of life!

This is a legal form that states who you want to make decisions about medical care.

The person is authorized to speak for you any time ONLY if you are unable to make your own medical decisions.

May also be called:

- "Health care proxy or agent"
- "Health care surrogate"
- "Durable power of attorney for health care"

It gives a much broader scope of decisions than the living will document.

Both forms are necessary to complete your advance directives and to protect your wishes for care at the end of life.

**Advantages of advance directives are:**

- You are in charge of making your own decisions
- Documents can be changed anytime
- You DO NOT need an attorney
- Documents can help you take initiative with family and doctor to express wishes

Messages here:

1. Discuss where to keep advance directives and not
2. Make sure you give your health care agent a copy of your AD, plus family and doctor
3. Always complete a medical power of attorney document, not just a living will!

Medical Terms for End-of-Life Care Decision Making

- Life-Sustaining Treatment
- Artificial Nutrition and Hydration (tube feeding)
- Cardiopulmonary Resuscitation (CPR)
- Do-Not-Resuscitate Order (DNR)
- Palliative Care
- Hospice


The identification of the main goal of care can facilitate the development of a care plan to serve as a road map toward that goal. The care plan speaks to specific interventions while the goal speaks to the overarching aim of care. The goal of care indicates the destination and the care plan signals the need for a discussion with the care team, including the resident if possible and the family, to strive to reconcile understanding and expectations. These discussions are important decision-making tools that can facilitate getting team members on the same page for providing care to the resident.

In figure 1, possible overarching goals of care are listed on the left as well as on the right to underscore that developing and changing of goals is a circular process. According to the Guiding Star Model, at any given time the overarching goal of care for each nursing home resident can be characterized by one of the mutually-exclusive options of comfort care, prolonging survival care, or combination care (each defined below). Some residents lack a clear goal of care and are represented in the model as “not clear”.

Throughout the illness trajectory the overarching goal of care can change. This model identifies factors that can affect the process of developing, maintaining, and changing the goal of care from the perspective of the family surrogate decision-maker. Regardless of the goal, it is important to attend to physical, social, emotional, and spiritual comfort concerns of all nursing home residents. Indeed, nursing home residents meet the criterial for receipt of palliative care based on guidelines set forth by the National Consensus Project for Quality Palliative Care (National Consensus Project, 2013) which include living with progressive conditions, and living with chronic and life-threatening injuries from accidents or other forms of trauma (pp. 8-9). Palliative care should be part of the care plan for each nursing home resident, regardless of the goal of care.
FIGURE 1 Guiding Star Model: Family goals of care surrogate decision-making process in the nursing home (Color figure available online).
XII. RESOURCES AND WEB PAGES

American Association of Notaries: https://secure.usnotaries.net/us/directory.asp


Traveling Notary Services: http://123notary.com/contactus.htm

The African-American Spiritual & Ethical Guide to End-of-Life Care

National Institutes of Health & National Institute on Aging www.nia.nih.gov/alzheimers

Talking with Your Older Patient http://www.nia.nih.gov/health/publication/talking-your-older-patient/foreword

Caring Conversations Materials www.caringcommunities.org,
http://www.practicalbioethics.org/resources/caring-conversations

Literature/Discussions:
https://www.socialworkers.org/practice/bereavement/standards/default.asp
http://www.socialworkpolicy.org/research/end-of-life-care.html
http://jco.ascopubs.org/content/31/27/3315.short?rss=1

Video: http://www.pbs.org/wnet/need-to-know/video/video-end-of-life-decisions/14965/

Social Work Resources:
http://www.calhospice.org/included/docs/education/9B_NFQSCompetencies %20Social%20Work.pdf

Interact Tool (Scroll down to the Advanced Care Planning Tools):

Missouri Bar DPOA:

National Health Care Decisions: http://www.nhdd.org/

Code Case Scenarios - Use for APRNs: http://www.codaalliance.org/caseexamples.html


The Rabbinical Council of America, Halachic Guidelines to Assist in EOL medical decisions:
http://www.rabbis.org/pdfs/hcpi.pdf
XIII. **REGULATIONS (U.S. GOVERNMENT PRINTING OFFICE, 2014)**

Center for Medicare and Medicaid Services, Department of Health and Human Services, State Operations Manual - Appendix PP - Guidance to Surveyors for Long Term Care Facilities -

F152

§483.10(a)(3) -- In the case of a resident adjudged incompetent under the laws of a State by a court of competent jurisdiction, the rights of the resident are exercised by the person appointed under State law to act on the resident’s behalf.

§483.10(a)(4) -- In the case of a resident who has not been adjudged incompetent by the State court, any legal surrogate designated in accordance with State law may exercise the resident’s rights to the extent provided by State law.

Interpretive Guidelines §483.10(a)(3) and (4)

When reference is made to "resident" in the Guidelines, it also refers to any person who may, under State law, act on the resident’s behalf when the resident is unable to act for himself or herself. That person is referred to as the resident’s surrogate or representative. If the resident has been formally declared incompetent by a court, the surrogate or representative is whoever was appointed by the court - a guardian, conservator, or committee. The facility should verify that a surrogate or representative has the necessary authority. For example, a court-appointed conservator might have the power to make financial decisions, but not health care decisions.

A resident may wish to delegate decision-making to specific persons, or the resident and family may have agreed among themselves on a decision-making process. To the degree permitted by State law, and to the maximum extent practicable, the facility must respect the resident’s wishes and follow that process.

The rights of the resident that may be exercised by the surrogate or representative include the right to make health care decisions. However, the facility may seek a health care decision (or any other decision or authorization) from a surrogate or representative only when the resident is unable to make the decision. If there is a question as to whether the resident is able to make a health care decision, staff should discuss the matter with the resident at a suitable time and judge how well the resident understands the information. In the case of a resident who has been formally declared incompetent by a court, lack of capacity is presumed. Notwithstanding the above, if such a resident can understand the situation and express a preference, the resident should be informed and his/her wishes respected to the degree practicable. Any violations with respect to the resident’s exercise of rights should be cited under the applicable tag number.

The involvement of a surrogate or representative does not automatically relieve a facility of its duty to protect and promote the resident’s interests. For example, a surrogate or representative does not have the right to insist that a treatment be performed that is not medically appropriate, and the right of a surrogate or representative to reject treatment may be subject to state law limits.
Procedures §483.10(a)(3) and (4)

Determine as appropriate if the rights of a resident who has been adjudged incompetent or who has a representative acting on his/her behalf to help exercise his/her rights are exercised by the legally appointed individual.

F155 §483.10(b)(4) -- The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive as specified in paragraph (8) of this section; and

F156 §483.10(b)(1) -- The facility must inform the resident both orally and in writing in a language that the resident understands of his or her rights and all rules and regulations governing resident conduct and responsibilities during the stay in the facility. The facility must also provide the resident with the notice (if any) of the State developed under §1919(e)(6) of the Act. Such notification must be made prior to or upon admission and during the resident’s stay. Receipt of such information, and any amendments to it, must be acknowledged in writing;

“Advance directive” means a written instruction, such as a living will or durable power of attorney for health care, recognized under State law relating to the provision of health care when the individual is incapacitated.

As provided under State law, a resident who has the capacity to make a health care decision and who withholds consent to treatment or makes an explicit refusal of treatment either directly or through an advance directive, may not be treated against his/her wishes.

§483.10(b)(8) -- The facility must comply with the requirements specified in subpart I of part 489 of this chapter relating to maintaining written policies and procedures regarding advance directives. These requirements include provisions to inform and provide written information to all adult residents concerning the right to accept or refuse medical or surgical treatment and, at the individual’s option, formulate an advance directive. This includes a written description of the facility’s policies to implement advance directives and applicable State law

Resident Choice

In order for a resident to exercise his or her right appropriately to make informed choices about care and treatment or to refuse treatment, the facility and the resident (or the resident’s legal representative) must discuss the resident’s condition, treatment options, expected outcomes, and consequences of refusing treatment. The facility is expected to address the resident’s concerns and offer relevant alternatives, if the resident has refused specific treatments. (See Resident Rights at 42 CFR 483.10(b)(3) and (4), F154 and F155.)

Advance Directive

A resident at the end of life, in terminal stages of an illness or having multiple system failures may have written directions for his or her treatment goals (or a decision has been made by the resident’s surrogate or representative, in accordance with state law).

If a resident has a valid Advance Directive, the facility’s care must reflect a resident’s wishes as expressed in the Directive, in accordance with state law. However, the presence of an Advance Directive does not absolve the facility from giving supportive and other pertinent care that is
not prohibited by the Advance Directive. If the facility has implemented individualized approaches for end-of-life care in accordance with the resident's wishes, and has implemented appropriate efforts to try to stabilize the resident’s condition (or indicated why the condition cannot or should not be stabilized) and to provide care to prevent or treat the pressure ulcer (including pertinent, routine, lesser aggressive approaches, such as, cleaning, turning, repositioning), then the development, continuation, or progression of a pressure ulcer may be consistent with regulatory requirements.

**NOTE:** The presence of a "Do Not Resuscitate" (DNR) order is not sufficient to indicate the resident is declining other appropriate treatment and services. It only indicates that the resident should not be resuscitated if respirations and/or cardiac function cease.

**End-of-Life**

Resident choices and clinical indications affect decisions about the use of a feeding tube at the end-of-life. A resident at the end of life may have an advance directive addressing his or her treatment goals (or the resident’s surrogate or representative, in accordance with State law, may have made a decision).

Decreased appetite and altered hydration are common at the end of life, and do not require interventions other than for comfort. Multiple organ system failure may impair the body’s capacity to accept or digest food or to utilize nutrients. Thus, the inability to maintain acceptable parameters of nutritional status for someone who is at the end-of-life or in the terminal stages of an illness may be an expected outcome.

Care and services, including comfort measures, are provided based on the resident’s choices and a pertinent nutritional assessment. The facility can help to support intake, to the extent desired and feasible, based on the information from the assessment and on considering the resident’s choices.

If individualized approaches for end-of-life care are provided in accordance with the care plan and the resident's choices, then the failure to maintain acceptable parameters of nutritional status may be an expected outcome for residents with terminal conditions.

**Advance Directives** - A resident may have written or verbal directions related to treatment choices (or a decision has been made by the resident’s surrogate or representative) in accordance with state law. An advance directive is a means for the resident to communicate his or her wishes, which may include withdrawing or withholding medications. Whether or not a resident has an advanced directive, the facility is responsible for giving treatment, support, and other care that is consistent with the resident’s condition and applicable care instructions.

**NOTE:** Choosing not to be resuscitated (reflected in a “Do Not Resuscitate” (DNR) order) indicates that the resident should not be resuscitated if respirations and/or cardiac function cease. A DNR order by itself does not indicate that the resident has declined other appropriate treatment and services.

**F271**

**§483.20(a) Admission Orders**

**§42 CFR 483.20(k)(1) and (2), F279, F280, Comprehensive Care Plans**

**§42 CFR 483.25(a)(1), F310, Decline in ADL**
XIV. REFERENCES


