



Implementation Guide:

Goal 6: Advance Care Planning

This Implementation Guide provides efficient, consistent, evidence-based approaches to advance care planning.

www.nhqualitycampaign.org

Revised 07/23/10

ADVANCING EXCELLENCE IN AMERICA'S NURSING HOMES

A Campaign to Improve Quality of Life for Residents and Staff

Advancing Excellence in America's Nursing Homes is a [national](#) campaign to encourage, assist and empower nursing homes to improve the quality of care and life for residents.

Comprised of long term care providers, medical professionals, consumers, employees, and state and federal agencies, *AE* is the largest and first coalition of its kind to measure quality by setting clinical and organizational goals for nursing homes.

The coalition stimulates quality improvements by providing nursing homes with free, current and practical evidence-based [resources](#), empowering residents and their families with education, and helping participants reach their targets. Homes can compare their progress with state and national averages.

This Implementation Guide was prepared by volunteers and members of the Advancing Excellence Steering Committee.

Click [here](#) to see a list of coalition leaders.

Goal 6: Advance Care Planning

Following admission and prior to completing or updating the plan of care, all NH residents will have the opportunity to discuss their goals for care including their preferences for advance care planning with an appropriate member of the healthcare team. Those preferences should be recorded in their medical record and used in the development of their plan of care.

Website Data Collection: What proportion of residents has a record of a discussion with an appropriate member of the healthcare team regarding their goals for care including their preferences for advanced care planning in their medical record and in their plan of care?


Objectives – By December 31, 2011:


A-1: Among all nursing homes participating in this goal, the average of the reported percent of newly admitted or re-admitted residents having discussions regarding their goals for care including their preferences for advance care planning recorded in their medical record and their plan of care will be at or above 75%.


A-2: Among all nursing homes participating in this goal, the average of the reported percent of residents having discussions during their quarterly care planning conference regarding their goals for care including their preferences for advance care planning recorded in their medical record and their plan of care will be at or above 75%.

ICON KEY

 Recognition/Assessment

 Cause Identification

 Management

 Monitoring

The icons in the box to the left will be used throughout this guide to help identify those processes related to key evidence-based approaches.

Approach to Implementation

A nursing home working to improve advance care planning should follow these steps:

Recognition / Assessment



1. *Identify advance care planning as an area for potential improvement in performance.*

- Based on state regulatory requirements, nursing home quality improvement data, quality measures, survey results, reviews of actual cases, comparison to benchmarks, etc.

2. *Identify authoritative information available about advance care planning.*

- Review state laws and regulations regarding advance care planning, advance directives, and related issues; references listed in the Advance Care Planning Resources, as well as reliable and evidence-based information about how to implement advance care planning, from the literature and from relevant professional associations and organizations.
- Identify ways to distinguish the reliability of information about implementing advance care planning (i.e., how to separate valid ideas from myths and misconceptions about the topic), keeping in mind that each state has state-specific laws and regulations about related processes.

3. *Identify current process and practices in the nursing home related to advance care planning.*

For an overview of the process, see the Advance Care Planning Process Review Tool and related Advance Care Planning Flow Diagram.

- Who in the nursing home decides on the approaches to address advance care planning, and what approaches do they currently use?
- Are the nursing home's approaches consistent with the steps identified in the Advance Care Planning Process Framework?

4. *Identify areas for improvement in processes and practices.*

Using the information gathered in Steps 2 and 3 above, compare current with desirable approaches to advance care planning. Address the following:

- Check whether current nursing home policies / protocols are consistent with desirable approaches.
- Check whether desirable approaches are being followed consistently.
- Identify whether anyone has been reviewing and comparing current approaches to advance care planning to desirable ones.
- Have issues related to advance care planning been identified previously? Were they followed up?
- Has the nursing home previously evaluated its performance and taken steps to improve?

Cause Identification



5. *Identify the causes of any issues related to advance care planning, including root causes of undesirable variations in performance and practice.*

- Identify issues and practices that impede reaching the goal of improving advance care planning.
- Identify underlying causes (including root causes) of, and factors related to, undesirable and inappropriate advance care planning in the nursing home.
- Identify reasons given by those who do not adequately follow desirable approaches.

Management



6. *Reinforce optimal practice and performance.*

Continually promote “doing the right thing in the right way.”

Follow the steps of the Advance Care Planning Framework, throughout the nursing home.

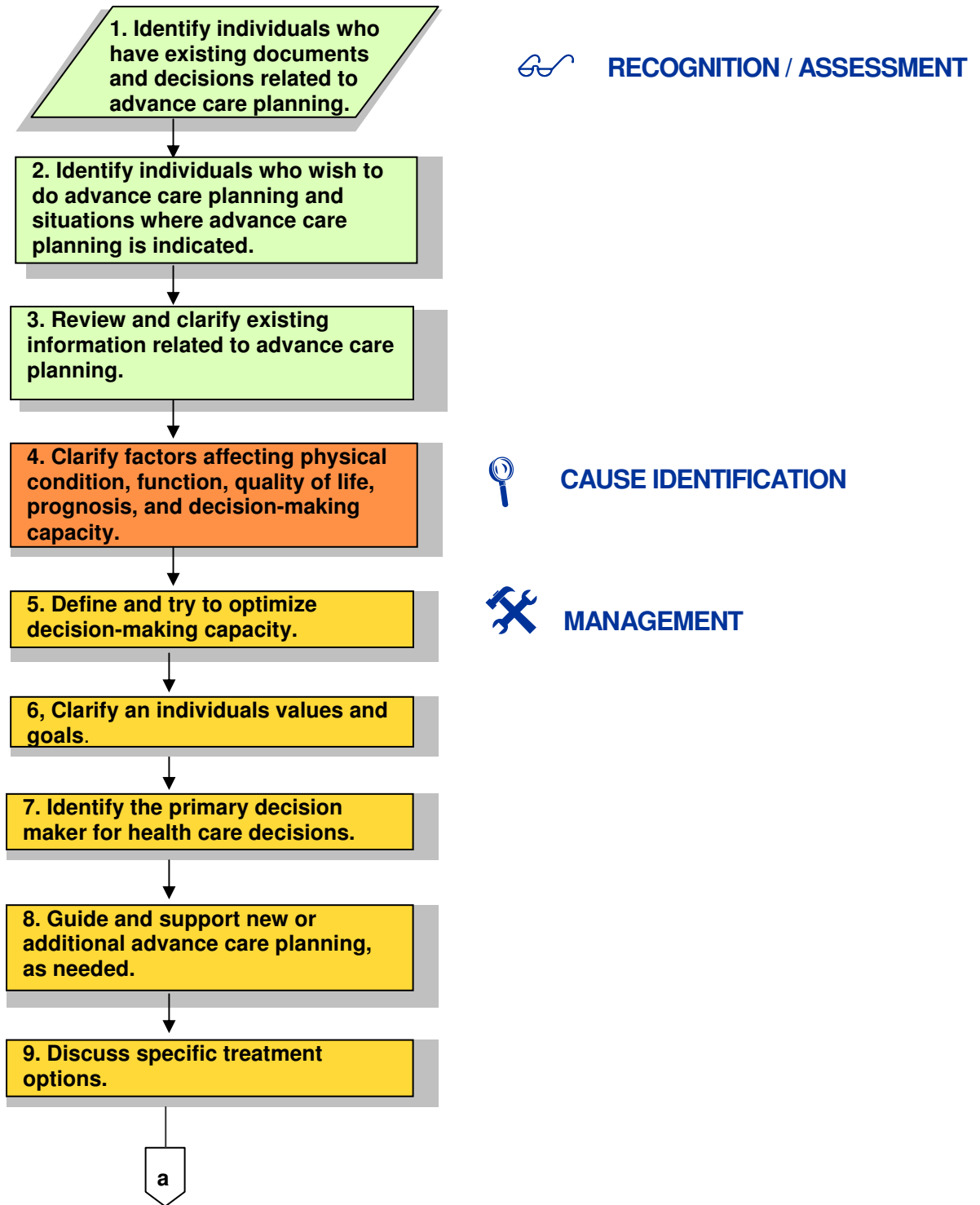
- Identify and use tools and resources to help implement the steps and address related issues.
- Based on information and data collected about the organization and the processes and results related to advance care planning, reinforce processes and practices that are already optimal.

7. *Implement necessary changes.*

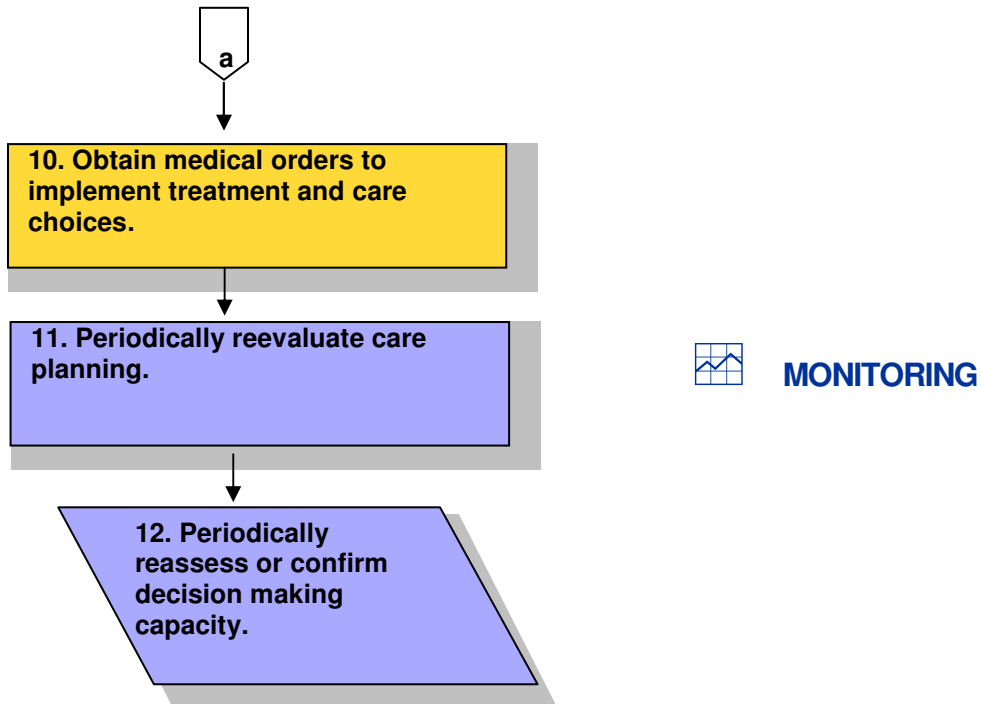
Address underlying causes (including root causes) of challenges and obstacles to addressing advance care planning effectively.

- Implement pertinent generic and cause-specific interventions.
- Address issues of individual performance and practice that could be improved in trying to improve advance care planning.
- Refer to Advance Care Planning Resources for resources and tools that can help to address this goal.

Flow Diagram – Advanced Care Planning Process Framework




Flow Diagram – Advanced Care Planning Process Framework (cont'd)






Advance Care Planning Process Review Tool

RECOGNITION / ASSESSMENT				
		YES	NO	N/A
1.	Did the staff identify a resident / patient's existing documents and decisions related to advance care planning?			
2.	Did the staff identify a resident / patient who wished to do advance care planning and a situation where advance care planning was indicated?			
3.	Did the staff and practitioner review and clarify any existing information related to advance care planning?			
CAUSE IDENTIFICATION				
		YES	NO	N/A
4.	Did the staff and practitioner identify and address factors affecting physical condition, function, quality of life, prognosis, and decision-making capacity?			
MANAGEMENT				
		YES	NO	N/A
5.	Did the staff and practitioner define and try to optimize decision-making capacity?			
6.	Did the staff clarify a resident / patient's values and goals?			
7.	Did the staff and practitioner identify a primary decision maker for health care decisions?			
8.	Did the staff and practitioner guide and support new or additional advance care planning, as needed?			
9.	Did the staff and practitioner discuss and document specific treatment options?			
10.	Did the practitioner provide specific medical orders to implement treatment and care choices?			
Monitoring				
		YES	NO	N/A
11.	Did the staff and practitioner periodically reevaluate a resident / patient's advance care planning situation?			
12.	Did the staff and practitioner periodically reassess or confirm a resident / patient's decision making capacity?			


ADVANCE CARE PLANNING PROCESS FRAMEWORK


CARE PROCESS STEP	EXPECTATIONS	RATIONALE
 PROBLEM RECOGNITION / ASSESSMENT		
<p>1. Staff identify individuals who have existing documents and decisions related to advance care planning.</p>	<ul style="list-style-type: none"> - Staff identify and obtain information from residents / patients who have already made decisions and/or completed documents regarding health care treatment options and advance care planning. - Staff copy and disseminate related documents, as indicated. 	<ul style="list-style-type: none"> - Some individuals have already participated in advance care planning and have made decisions and/or documented their wishes. - Documents must be current and available for those who need to review them at various times (e.g., practitioners, nurses, Emergency Medical crews). - The facility needs a systematic approach, with assigned responsibility, to ensure that they have current versions of critical documents.
<p>2. The staff and practitioners identify individuals who wish to do advance care planning and situations where advance care planning is indicated.</p>	<ul style="list-style-type: none"> - The staff inform the residents / patients of their right to advance care planning and to make advance directives, and, as needed, they assist those who wish to do advance care planning. - The staff and practitioners identify situations (e.g., terminal condition, progressive irreversible decline in function) that warrant discussion of treatment options and documentation of specific choices. 	<ul style="list-style-type: none"> - Federal and state laws and regulations require health care providers to inform individuals of their right to make health care decisions and document advance directives. - Some potential treatment and care options may not be consistent with a person's condition, prognosis, values, and wishes.

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
PROBLEM RECOGNITION / ASSESSMENT (cont'd)		
<p>3. The staff and practitioners review and clarify existing information related to advance care planning.</p>	<ul style="list-style-type: none"> - The staff review existing documents for clarity, specificity, internal consistency, and compatibility with applicable laws and regulations. - The staff discuss with residents / patients and/or their families the content and implications of existing advance care planning documents. 	<ul style="list-style-type: none"> - Documents may be general, vague, incomplete, self-contradictory, or inconsistent with applicable laws and regulations; or, they may place conditions (e.g., confirmation of a terminal or persistent vegetative state) on implementation or withholding of specific treatments. - Residents / patients and their families may be unfamiliar with the content, or unclear about the implications of, their own advance care planning documents or those of the person for whom they are acting.
 CAUSE IDENTIFICATION / DIAGNOSIS		
<p>4. The practitioners and staff clarify factors affecting a person's physical condition, function, quality of life, prognosis, and decision-making capacity.</p>	<ul style="list-style-type: none"> - The practitioners and staff clarify an individual's current situation (e.g., their risk factors and active illnesses, problems, and impairments). - The practitioners help define prognosis (e.g., how likely is someone to stabilize, improve, decline, or die). - The staff and practitioners clarify the impact of a person's medical conditions and existing impairments on their function and quality of life. 	<ul style="list-style-type: none"> - Defining an individual's conditions, illnesses, problems, impairments, and risks is key to identifying situations where advance care planning is urgent, for understanding the relevance and risks of treatment options, and for recognizing factors affecting decision making capacity. - Medical conditions affect function and quality of life, and impact the potential for improving someone's overall status and prognosis. - Identification of underlying causes of impaired function and quality of life is essential to help identify potentially helpful interventions.
 MANAGEMENT		
<p>5. The staff and practitioners define and try to optimize decision-making capacity.</p>	<ul style="list-style-type: none"> - The staff and practitioners perform assessments needed to identify decision-making capacity. 	<ul style="list-style-type: none"> - Clarifying decision making capacity is essential to optimizing individual participation in personal and health care decisions.

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
	<ul style="list-style-type: none"> - The staff and practitioners reconcile diverse opinions about decision making capacity. - The staff and practitioners document the basis for conclusions about a person's decision making capacity, including factors influencing the determination. - The staff and practitioners address, as appropriate, treatable underlying causes (e.g., lethargy, delirium, medication side effects, visual impairments) of impaired mental and physical function that affect decision making capacity. 	<ul style="list-style-type: none"> - Decision making capacity is a functional capability that it is influenced by medical conditions, existing functional impairments, and psychosocial factors. A single test or assessment result is not necessarily definitive. - Decision making capacity determinations should be based on performance over time, not just on one occasion. - There is guidance published about determining decision-making capacity. - Decision making capacity is not "all-or-none;" it can be partial, at several levels. - Laws and regulations usually require that a practitioner confirm decision-making capacity, although a valid determination typically needs some input from others. - Different opinions about a person's decision-making capacity should be reconciled, to avoid complications related to the decision making process. - It is important to know how a conclusion about a person's decision-making capacity is reached, as various assessors may use different criteria.
<p> MANAGEMENT (cont'd)</p>		
<p>6. The staff clarify an individual's values and goals.</p>	<ul style="list-style-type: none"> - Staff identify and clarify an individual's values, goals, and wishes related to treatment choices and advance care planning preferences, including end-of-life care. 	<ul style="list-style-type: none"> - Interventions (e.g., hospitalization, medical testing, resuscitation, and artificial nutrition and hydration) should be relevant to a person's values, goals, wishes, and prognosis. - People often need help to understand how specific treatment options might relate to their general goals and wishes.

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
<p>7. The staff and practitioners identify the primary decision maker for health care decisions.</p>	<ul style="list-style-type: none"> - The staff and practitioners define a resident / patient 's role in making health care decisions, based on determining decision making capacity and on other factors including applicable laws and regulations. - The staff identify a primary decision maker, based on relevant considerations. - The staff identify others in addition to the primary decision maker who may be involved in guiding advance care planning decisions, consistent with applicable laws and regulations. 	<ul style="list-style-type: none"> - State laws and regulations typically specify who should be involved in decision-making capacity determinations and a process for certifying a person's decision-making capacity. - A resident / patient's role in advance care planning depends on the extent of their decision making capacity, family considerations, and other factors. - A resident / patient may still be able to participate to some extent in advance care planning even if someone else is the primary decision maker. - States typically have some restrictions and process requirements for substitute decision makers.
<p> MANAGEMENT (cont'd)</p>		
<p>8. The staff and practitioners guide and support new or additional advance care planning, as needed.</p>	<ul style="list-style-type: none"> - The staff and practitioners assist residents/patients who wish to develop an advance directive or who want to modify an existing one. - The facility assigns responsibility for various facets of the advance care planning process, depending on the need for individuals with specific skills, knowledge, credentials, etc. - When a substitute decision maker is involved, staff guide them regarding their roles and relevant procedures (e.g., those required under state laws). 	<ul style="list-style-type: none"> - Many individuals need additional information and assistance to make or update treatment choices. - Additional decisions may be needed as issues arise. - Practitioners may need to discuss the relevance and advisability of specific treatment options, whereas knowledgeable social workers and nurses can give general guidance on procedural issues.
<p>9. The practitioners and staff discuss specific treatment options.</p>	<ul style="list-style-type: none"> - The staff and practitioners define specific issues that need discussion or decisions; e.g., whether to resuscitate, hospitalize, or provide artificial nutrition and hydration. - The practitioners and staff discuss the pertinence, benefits, and risks, of various 	<ul style="list-style-type: none"> - It is important to clearly and correctly identify the issues before trying to address them. - Documentation of the advance care planning process is important to show that required steps and other desirable procedures were followed.

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
	<p>treatment options, and they document such discussions.</p>	<ul style="list-style-type: none"> - “Pertinence” relates to the individual’s overall condition and prognosis, available treatments, treatment goals, overall personal goals and wishes, and the presence of conditions or risks that may affect the likelihood of desirable outcomes. - How and by whom information is presented often influences a decision maker’s understanding of issues and the likelihood that they will make appropriate decisions. - CPR status should be distinguished from wishes about treatment prior to cardiopulmonary arrest. - Treatment choices should be compatible; however, it is possible to desire interventions prior to a cardiac arrest but to not want cardiopulmonary resuscitation (CPR), or to want CPR but not certain other treatments.
<p> MANAGEMENT (cont’d)</p>		
<p>10. The staff obtain medical orders to implement treatment and care choices.</p>	<ul style="list-style-type: none"> - The practitioners give medical orders to implement treatment and care choices. - Staff clarify that orders are clear, complete, and consistent with documented choices. 	<ul style="list-style-type: none"> - Orders are needed to implement specific choices to withhold or withdraw treatments. - Orders should be consistent with valid choices made by a resident / patient or a substitute decision maker, or disparities should be explained (e.g., because there were conflicts among family members or because treatment requested by a patient or family was deemed to be medically ineffective, based on definitions in state law). - Orders should be consistent with applicable laws and regulations; e.g., regarding who can write such orders and what related documentation is needed. - Orders should specify relevant aspects of any palliative care plan; that is, what exactly will not be

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
		<p>provided.</p> <ul style="list-style-type: none"> - General orders such as “comfort care” or “palliative care” are too vague to guide precise and consistent interpretation.
<p> MONITORING</p>		
<p>11. The staff and practitioners periodically reevaluate situations related to advance care planning.</p>	<ul style="list-style-type: none"> - The staff and practitioners periodically reevaluate an individual's condition, prognosis, and wishes, and help residents / patients update existing care instructions and documents as needed. - The staff and practitioners continue or adjust approaches as needed. 	<ul style="list-style-type: none"> - Residents / patients have the right to change or revoke their advance directives, and substitute decision makers can change their instructions within limits (e.g., they must remain consistent with someone's documented wishes), but states often impose specific procedural requirements to do so. - An individual's situation may change with time, or the individual or substitute decision maker may change their wishes about treatment choices. - Sometimes, new or revised documents and orders are needed to implement revised or new treatment choices. - Updating should be done within a time frame that is relevant to changes in an individual's prognosis, condition, and wishes.
<p>12. The staff and practitioners periodically reassess or confirm decision making capacity.</p>	<ul style="list-style-type: none"> - The staff and practitioners reevaluate a person's decision-making capacity over time, or verify that it is unlikely to change further. 	<ul style="list-style-type: none"> - Decision making capacity may change with time, as resolution of existing conditions or onset of new illnesses and condition changes may influence it.

ADVANCE CARE PLANNING RESOURCES

For Professionals

- | | |
|---|--|
| 1 | Molloy DW, Darzins P, Strang D. Capacity to Decide. Winchester, MA:Newgrange Press, 1999. |
| 2 | Marquis DK. Advance Care Planning: A Practical Guide for Physicians https://catalog.ama-assn.org/Catalog/product/product_detail.jsp?productId=OP318800+ (American Medical Association) |
| 3 | Alzheimer's Association Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes Phase 3: End of Life Care http://www.alz.org/national/documents/brochure_DCPRphase3.pdf |

For Consumers

- | | |
|----|---|
| 4 | Lynn J, Harold J. Handbook for Mortals: Guidance for People Facing Serious Illness. Oxford University Press, 1999. |
| 5 | State specific advance directive forms through Caring Connections: http://www.caringinfo.org/AdvanceDirectives (National Hospice and Palliative Care Organization) |
| 6 | Own Your Future Campaign kit http://www.longtermcare.gov/LTC/Main_Site/Planning_LTC/Campaign/Kit/index.aspx (U.S. Department of Health and Human Services) – includes information on long term care and legal planning |
| 7 | Personal Health Record http://www.myphr.com/ (American Health Information Management Association) – public awareness campaign that emphasizes importance of maintaining your own record |
| 8 | Consumer's Tool Kit for Health Care Advance Planning – ABA Commission on Law and Aging http://www.abanet.org/aging/toolkit/ |
| 9 | Decisions about End of Life Care http://jama.ama-assn.org/cgi/reprint/284/19/2550.pdf (American Medical Association) |
| 10 | Advance Directives for End of Life Medical Decisions http://jama.ama-assn.org/cgi/reprint/283/11/1518.pdf (American Medical Association) |
| 11 | End of Life Care: A Guide for Patients and Caregivers http://www.healthinaging.org/public_education/pef/end_of_life_care.php (American Geriatrics Society) |
| 12 | http://www.nlm.nih.gov/medlineplus/advancedirectives.html |
| 13 | http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp |

Informational Resources

- | | |
|----|--|
| 14 | Describing Death in America http://www.nap.edu/catalog.php?record_id=10619 or http://books.google.com/books?id=NUA2PUdl9XAC&dq=Describing+Death+in+America&printsec=frontcover&source=bn&hl=en&ei=MFNATLCINoS0IQeRy8W1Dg&sa=X&oi=book_result&ct=result&resnum=4&ved=0CCIQ6AEwAw#v=onepage&q&f=false (Institute of Medicine) |
|----|--|